THE REALITY OF RIGHTS, INDEPENDENCE, CHOICE AND INCLUSION FOR ADULTS WITH LEARNING DISABILITIES

John Richard PRESLAND

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Abstract

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J.R. PRESLAND

ABSTRACT

The aim of this qualitative research study is to explore the reality of rights, independence, choice and inclusion for adults with learning disabilities; these represent key principles in government policy on this service user group, as set out in *Valuing People* (2001). The role of professionals (specifically Care Managers) in acting as allies to people with learning disabilities is also considered. The literature review explores the impact of social policy, the interventions arising from it, and the role of professionals, in the lives of people with learning disabilities over the last one hundred years. Focus Groups are used to explore the themes emerging from the literature review with a local group of people with learning disabilities and Care Managers. Originally Direct Payments and now Personal Budgets offer a means of making choices outside of specialist services. Expectations of people with learning disabilities regarding the relationships and models of support to which they aspire are explored, together with issues of communication – written and verbal. The importance of connecting people's past influences and experiences with the present and future are identified, acknowledging that the story of social policy is also a personal story of people's lived experiences. The dilemmas Care Managers face in carrying out their assessment role also emerge from the research. The application of social work values and reflective practice for Care Managers is identified as a significant aspect of professional practice.

In memory of my mother, Enid Presland (1920-1972), whose early death denied us the opportunity to share anything of my professional and academic journey

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Amanda Silk

1. Introduction

1.1 Research Aims

The aim of this research is to explore the reality of rights, independence, choice and inclusion for adults with learning disabilities; these represent key principles in government policy on this service user group, as set out in *Valuing People* (2001, p.3 para 4). This same paragraph states that legislation, such as the Human Rights Act 1998 and the Disability Discrimination Act 1995 (subsequently replaced by 2010 Equality Act), which confers rights on all citizens, applies equally to people with learning disabilities. The accessible (sometimes called 'easy read') version of *Valuing People,* produced for people with learning disabilities shortly after the publication of the White Paper, 'translates' the four key principles into 'people with learning disabilities are citizens too'.

The research focuses on the experiences of six people with learning disabilities (four men and two women; age range 40-68) who belong to an organisation called Right Track[1]. They have participated, in different ways, in the implementation of *Valuing People* (2001), with its specific focus on four *key* principles for the individual person with a learning disability (Race 2007, p.88). Reorganisation of local government in the last fifteen years has divided the services originally provided by one County Council into three smaller geographical locations. Right Track, which was formed in May 2006, became a Community Interest Company (CIC) in June 2011. It is contracted to work with

[1] See Appendix 2.

one of the three new local authorities on providing information to people with learning disabilities.

Right Track's early objective was supporting people with learning disabilities to understand direct payments, and to represent their views to the local authority; later it picked up on the developing agendas of individual budgets, self-directed support and personalisation within the field of adult social care (see appendix 1 for overview of terminology). All these policy interventions are arguably underpinned by the concept of greater choice and control for the individual, initiated by direct payments. At their inception, in 1996, direct payments provided individuals with the cash equivalent of a directly provided service. Their stated purpose was: *'to give people control over their own life by providing an alternative to social care services provided by a local council' (*Department of Health: 2003), and they were subsequently recognised as offering greater flexibility and quality in support (Leece and Bornat 2006, p.100; Glasby and Littlechild 2009, p.111; Stainton and Boyce 2004, p.449).

The point is made that the principles which underpin 'cash instead of services' changes the nature of relationships; a changing relationship between the state and the individual which impacts on service users and their families, as well as the professionals (and their managers) who work with them (Glasby and Littlechild 2009, p.22). It is the relationships that people with learning disabilities experience as they consider the new options of support and services available through the direct payment model that is a key feature of this research. The requirement for people to 'consent' to direct payments and be able to 'manage' them originally excluded people with learning disabilities (Direct Choices 2004). An essential aspect of the research question relates to the role of professionals (in this situation it is specifically Care Managers) in acting as allies to people with learning disabilities who have aspirations for direct payments or personalised budgets as one means of achieving the principles of *Valuing People*. The concept of 'allies' can be important to people in many aspects of their lives; who plays that role, the approach,

skills and knowledge they need to be an ally, depend upon a range of circumstances. I will explore that here through a series of interlinked focus groups involving people with learning disabilities and care managers. Finally, the story of direct payments also illustrates the challenges people face with taking up independence and choice (Stainton and Boyce 2004).

1.2 Stages of the Research

The first stage of the research will be a detailed systematic literature search (Hart 2005, p.28). The economic and social issues that led to the 1913 Mental Deficiency Act will be the starting point, through to *Valuing People* (2001) and *Valuing People Now*[2] (2009), to explore how disability has been conceptualized and re-conceptualized over time. The research participants' personal experience has been very much shaped by the 'service model' of social care that developed from the 1971 White Paper '*Better Services for the Mentally Handicapped'*, which set out *general* principles for services to the 'handicapped person and his family'. Thus its inclusion in this study, together with its antecedents, provides a context for the lives of the generation of people with learning disabilities represented in this study. This analysis will illuminate the negative perceptions of learning disability that have existed over time, and how these have influenced policy and the development of services and the role of professionals associated with those services.

The second stage begins with Focus Group (One) made up of the six people with learning disabilities referred to earlier who explore their life experiences together in the focus group. These themes are then taken to Focus Group (Two) of staff in the local learning disability social work team. A joint Focus Group (Three), made up of people with learning disabilities and professionals, explores the themes that emerge from the first two groups, highlighting similarities and differences in expectations on ways forward. Because direct payments have been such an central part of participants' work

[2] Consultation with stakeholders took place in 2007-08; the report was published in January 2009.

in Right Track, a role-play in which people with learning disabilities were 'assessed' by Care Managers for a direct payment of their choice was used to explore some of the pivotal issues around the experience of making choices.

1.3 People with Learning Disabilities

People with a learning disability are a minority group within our society, described as one of the most marginalised groups in Western society (Hall, 2005, p.107). They, and issues about their lives, can so easily be confused in the minds of wider society with people with physical and sensory impairments, and people who face mental health issues. Who they are then is an important question. Within UK policy 'learning disability' refers to:

> …a condition which started before adulthood, with a lasting effect on development including a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning). (*Valuing People* DOH 2001: p14).

On the face of it, this appears to be a straightforward definition but *Valuing People* goes on to explain that the definition covers a wide range of people. An IQ quotient of below 70 has, historically, been used as a measure (Williams and Evans 2013, p.3), but this measure does not, by itself, indicate the need for an individual to receive additional health and social care support. An additional assessment of social functioning and communication skills of the individual person is essential to determine need for intervention (*Valuing People* 2001, p.2, para 1.6).

There are few groups whose terminology (or labels) has changed so rapidly as those for this particular group of people (Welshman and Walmsley 2006, p.6). The earlier term 'mental defective' referred to organic and irreversible damage, a very different understanding to the present term 'learning disability'. This acknowledges problems

with cognitive functioning, but concentrates on people's capacities and how these can be enhanced by education and support. The words imbecile, idiot and feebleminded are associated with the 1913 Mental Deficiency Act[3], whilst the words 'difficulty' and 'disability' following the word 'learning' reflect the debates around the use and meaning of words that have been part of the last 25 years or more, since education became a universal right for children of all IQ levels. The People First movement (Williams 2006, p.2), favours 'learning difficulty', although the government has used 'learning disability' throughout *Valuing People,* justifying this by saying they want to avoid confusion with educational terms that define difficulties but do not affect intelligence.

The use of the term 'learning disability' throughout this thesis (other than the use of historical terminology where this supports clarity) was the choice of the people with learning disabilities who participated in the Focus Groups. A learning disability is one aspect of their being, but that one aspect should not be seen as a total determinant of their personality and being (Bigby and Frawley 2010, p.2). They also share the label of learning disabilities with many other people in the United Kingdom and across the world, but they are not a homogeneous group, they are individuals; an objective of this research is to illuminate their individual stories, and how they have been shaped by local experiences; identifying where those experiences may add to a broader debate about learning disabilities, and its place in society, is a subsidiary objective.

1.5 An emerging challenge

This research was approved under the procedures set out by the University of Bedfordshire and, as such, traditional ethical principles were to be applied. There was an implicit understanding that the researcher's background – previously working with the same local authority that originally provided services to the people with learning disabilities participating in the research, as well as the social work team, and

[3] See appendix 5.

subsequently working as an advisor to Right Track, would raise the issue of 'insider research'. As the research continued along traditional lines – literature review, focus groups which were audio taped, transcribed, and then analysed – the ground began to shift and the researcher realised that there were issues concerning 'ownership' of the research; the experiences which people with learning disabilities talked about and then transferred onto graphics belonged to them. For them, I believe, the main 'benefit' of participating in this research, and its activities such as the role-play, was the opportunity to enhance and promote their work with Right Track. They wanted their views to be attributed to them and the work of Right Track. On the one hand, this challenged the original research concept, particularly ethical considerations around confidentiality; on the other, not to meet their expectations contradicted the principles of rights, independence, choice and inclusion which this research is all about. These issues are discussed further in the methodology chapter and the conclusion; they are not resolved within this study, but the scene is set for the possibilities of further research work based on the principles of participatory/inclusive and action research.

The next chapter, the literature search, takes an historical perspective, seeking to identity how changing economic and social policy – and perceptions of people with learning disabilities – impacted on their lives.

2. Literature Review

2.1 Overview

This literature review traces the history of people with learning disabilities in terms of how they have been viewed and treated by society, or more specifically social policy. Social policy assists us to appreciate the intricacies of modern society; how it is maintained, and then how change occurs. One measure of the importance of social policy is that it is often the single largest area of government spending, making the provision of welfare a significant factor in the economies of industrial societies (Baldock *et al* 2012, p.8). The review findings are set out within a framework of social policy relevant to learning disabilities which suggests a three-stage shift in the place of people with learning disabilities in UK society: firstly, the non-citizen, perceived as dependent but with an increasing emphasis on the need for control; secondly, the welfare citizen, with an emphasis on care; and thirdly, the aspiration to active citizenship which has been the goal of *Valuing People* (2001) and subsequent developments in adult social care more generally.

This review aims to identify the reality of policies in the daily lives of people with learning disabilities through the services or interventions that have emerged from social policy, and the role of professionals associated with those services. The continued significance of economic imperatives on the perception and treatment of people, from the Industrial Revolution to the present, is acknowledged; including the initial fostering, then curtailment of welfare citizenship, and the closure of long-stay institutions announced in 1961 by Enoch Powell, which was criticised by academics as primarily motivated by the promise of saving money (Race 2002, p.37). Later, thirty years on, the 1990 NHS and Community Care Act was seen by many to be principally a response to

the escalating costs of social security (Brenton and Ungerson 1989, p.145; Means, Richards and Smith 2008, p.51), while current agendas for personalisation have appeal as a cost-cutting exercise (Needham 2011, p.3). Overall, a core approach of low taxation (May, Brunsden and Craig 1997, p8) was, by 1997, a shared goal of the main political parties; this replaced the earlier, more distinct ideologies, on social and economic policies identified in a Conservative or Labour manifesto. If this shared approach to taxation is to be achieved, a core objective for a government of any political persuasion is strict management of publicly-funded welfare and an awareness of fiscal constraints decreed by a progressively more globalised economy. Where policies and intervention changes are examined for their impact on perceptions and relationships - the focus of this research - it is acknowledged that those same changes can legitimately be seen to be influenced by political goals of expenditure reduction. However, this research seeks to highlight 'the other side of the coin', not to contest the arguments which call attention to the important influence of economic imperatives.

Although top-down economic imperatives are generally presented as the reason behind policy change, bottom-up pressures have been an influence on policy change. Developments in learning disabilities services have often been seen as pioneering (Whitehead 2008), for example, in the early development person-centred planning, but people with learning disabilities have not been part of the mainstream disability movement; the major influences on social policy have a wider disability context based on physical and sensory impairments, represented by a strong social movement which has successfully challenged the concept of disability as an individual pathology, and reconstructed it as a social model of disability (Oliver 1998). Campaigns over a long period – eventually with success – resulted in legislation enabling local authorities to make direct payments as an alternative to directly provided community care services (Glasby and Littlechild 2009, p.30). People with learning disabilities have benefitted from the outcomes of these campaigns; but not without some difficulties, suggesting they have attributes which are not yet fully accommodated in the thinking of either the

wider community, or some disability activists. This difference has been apparent since the writing of the philosopher John Locke (1689) positioned intellectual disability as a permanent inability to reason (Race 2002, p.25). This powerful concept of 'difference' has marginalised people with learning disabilities – early nineteenth century perceptions suggested they were biologically different, even 'sub human' - and, in more recent times, structured oppression, such as segregated services, has made it difficult for all but a few to 'speak for themselves' and challenge negative imagery (Thomson 1998, p.22; Race 2002, p.26; Walmsley 1991, p.220).

The framework used for this literature review is a heuristic device. In reality, policy initiatives can become merged and blurred; implementation can be delayed; and the ambiguity of central policy allows different interpretations locally (Baldock 2012, p.13). The exact nature and timing of changes in the lives of people with learning disabilities and their families can, therefore, differ from that presented in policy.

Relationships between people with learning disabilities and significant people in their lives have previously been defined largely by concepts such as normalisation, and enacted through advocacy and person-centred planning. These latter two concepts were a key part of the *Valuing People* (2001) strategy, but the consultation preparing for *Valuing People Now* (DH 2007) revealed they were not fully understood by everyone, and there were concerns about progress in meeting the original goals (Whitehead 2008, p.4).

2.2 Non-Citizenship

This review starts with events leading to the 1913 Mental Deficiency Act, a landmark in establishing twentieth-century perceptions of mental deficiency that denied people

both rights and citizenship, and placed them in a position of dependency upon others. Mental deficiency was the generic term for what is now described as learning disabilities (or difficulties). Walmsley (1991, p.222) suggests the Act 'represents the nadir of the civil rights of people with learning difficulties' in Britain. At the beginning of the twentieth century mental deficiency, in particular a new category of 'feeble-mindedness', provided an explanation for the failings of social policy. For children who failed in school, adults who failed to respond to the regime and discipline of the workhouse and recidivist criminals, it was believed that they were not wilfully refusing to respond to education and just punishment; they were unable to do so because of inherited mental deficiency which meant they lacked the capacity to reason and therefore to change. The extent of this biological difference fed eugenic fears[4] of national degeneracy, which demanded an effective response, and raised questions as to whether the mentally deficient were part of the human race (Thomson 1998, p.22 Race 2002, p.26; Atherton 2007. p.50). Procreation and mental deficiency raised the fear of transmitting mental deficiency to future generations. Mental deficiency was also a class issue – strongly associated with the poor.

Economic imperatives associated with the Industrial Revolution, from the end of the eighteenth century, significantly impacted on society in England in the shift from a dominant, subsistence-based, rural economy to an urban industrial, waged-based one[5] (Atherton 2007, p.49). Sustaining a disabled member was easier than in an urban, disciplined and complex industrial society requiring new

practical and social skills. Care began to shift away from the family towards ideologies based on institutionalisation and professional/medical methods of care (Goble 2006, p.41). The introduction of universal elementary education, in 1870, brought in educational classification turning mental deficiency into a public affair; school leavers

[4] A term coined by Francis Galton in 1883, referring to the science of improving inborn human qualities through selected breeding.

[5] Many people would not have been able to read and write in a rural society; new demands were made in a 'technical' urban industrial society.

(Thomson 1998, p.13), who could not make the contribution to the economy, or the army, failed a vital economic test of social efficiency required to fulfil Great Britain's imperialist objectives (Borsay 2005, p.99).

The establishment, in 1904, of a Royal Commission on the Care and Control of the Feeble–Minded resulted in the 1913 Mental Deficiency Act[6]. The legislation underpinned classifications of mental deficiency that, along with the institutions to which they gave rise, remained in place for nearly fifty years. Medical science became the means of classifying people so that they could be legitimately excluded from the paid economy, and from citizenship status, on the basis that they did not conform to the norms of able-mindedness.

2.2.1 Interventions

The impact of the 1913 Mental Deficiency Act was to place 'mental deficiency' into a new, separate administrative category under the control of the Board of Control, and local Mental Deficiency Committees, who oversaw a system of 'care' in large institutions, physically separated from the locality (Thomson 1998, p.77). Places in the institutions were limited, however, and many people lived at home with their families, both the person with learning disabilities and the family under strict scrutiny from a representative of the local Mental Deficiency Committee (Thomson 1998, p.157). The practice of institutionalisation, associated with much of the nineteenth century, is not the full picture; community care, by families, was an important adjunct to that practice, not purely a late nineteenth-century development as it is often presented.

The 1927 Mental Deficiency Act confirmed government faith in specialised medical care as an appropriate response; education authorities were given greater powers to notify local mental deficiency boards of school leavers, while local authorities were required to provide the support of day centres for those living in the community. The colony model transferred from local authorities and became a hospital overnight, joining the newly

[6] See appendix 5.

created National Health Service in 1948. However, learning disabilities was to be something of a 'backwater' within the NHS, and the negative values of the past forty years were part of the transfer, a foundation for the medical model of learning disability (Race 2002, p.33).

2.2.2 Professionals

From 1834, as specialist institutions developed, it was the medical profession that dominated. A medical model of learning disabilities was seen as an effective – albeit humanely represented - means to segregate and control. At that time[7], medical classifications of people were seen as progressive and caring in the sense of identifying people who were vulnerable, and who should be protected from a harsh external world; however, from another perspective, the person is then primarily identified by their condition, effectively carrying a label of 'abnormal', whilst specialised medical practice separated them from the wider population and from people categorised with other types of impairment. Escalating costs for poor relief led to the 1834 Poor Law (Amendment) Act, a system of workhouses, managed locally, but now with centralised control and the key principle that 'relief' would be less attractive than self-help (Payne 2005, p.32). In 1948, marking the end of the Poor Law, its institutions and systems transferred to local government social work agencies.

The underpinning principle of the charity movement that preceded social work was that welfare must not curb work and self-help. The London Charity Organisation Society (COS) developed methods to investigate and 'assess' (the beginnings of social casework), whether people were deserving of help, and saw themselves are working with the 'deserving', the 'undeserving' being the responsibility of the Poor Law (Payne 2005, p.36).

[7] The nineteenth century.

2.3 The Welfare Citizen

The end of the Second World War was the starting point of a period of significant change in the story of people with learning difficulties, although qualified by doubts as to whether they experienced the degree of change suggested by shifts in language (Welshman and Walmsley 2006, p.1). A post-war Labour Government introduced an enhanced welfare state offering increased standards of living through jobs, homes, education, health; these benefits were now based on rights and encompassed the middle classes (Mitton 2012, p.320). The link made between mental deficiency with the lower classes, that so influenced thinking at the turn of the nineteenth century, was now challenged by the presence of mental deficiency in families who were clearly part of the post-war middle classes. However, changes in education and health policies contributed virtually nothing to either change or opportunity for people with learning difficulties. The 1944 Education Act categorised children with learning difficulties as 'uneducable' and excluded them from the education system. The arrival of the National Health Service (NHS) was an example of a benefit for the majority, but the inclusion in that service of mental deficiency institutions did little to support any aspects of citizenship for people with learning difficulties (Race 2002, p33). Parents' campaigns, fuelled by the failure of the 1944 Education Act to embrace their children, fought for their recognition as fully human, and for the services to match, a position denied to them by eugenic principles (Rolfe *et al* 2005). Parents formed the influential National Society for Mentally Handicapped Children in 1955, shortened to 'Mencap' in 1969 (www.mencap.org.uk/). Nonetheless, parents in the 1950s and 60s had a difficult time. Where an obvious condition was present at birth, such as Down's syndrome, the general advice was to leave the baby in the care of the NHS; and without the support of school, any parent opting to care for their child had little support, beyond some respite in hospital.

Research contributed to a shift in the understanding and perceptions of mental deficiency, and the classification criteria used for hospital admission. The work of Jack

Tizard and Neil O'Connor (1954), and separately Brandon's (1960), (Welshman and Walmsley 2006, p.26; Race 2002, p.34), drew attention to problems leading to categorisation that were social as opposed to intellectual in nature suggesting people could be successfully supported in the community. IQ, it appears, was not a fixed entity and environmental factors, for example, could be influential. Alongside this institutionalisation was the subject of sociological research during the 1960s, notably the work of Goffman (1961), and here in Britain, Pauline Morris's study of institutions (1969), drew attention to the highly negative cultures of institutional life[8].

(White Paper) Better Services for the Mentally Handicapped 1971

The outcomes of research, successful parental campaigns, and the public inquiry into the scandal and abuse at Ely hospital in Cardiff (1968), collectively contributed to a shift in government policy for all long-stay institutions. By 1971, in the case of people with learning difficulties, the result was a significant White Paper, *Better Services for the Mentally Handicapped*[9]*.* Atherton (2007, p.58) identifies its importance as the first social policy document to deal specifically with learning disabilities since 1913. The White Paper proposed a 50 per cent reduction in hospital places by 1991, and an increase in local authority-based residential and day care; it also suggested an end to custodial methods of care in hospitals; and the retraining of hospital staff. Although the 1971 White Paper was based on the principle that the mentally handicapped should not be 'unnecessarily segregated' from others, however, it did not address the question of whether hospital was the right place for any mentally handicapped person. The White Paper proposed a shift in priority from hospital to community care, with a firm focus on supporting the caring role of families with a handicapped member, identifying their need for 'general social services as all other families, as well as special additional help' (Race 2007, p.89). By 1987, recognising that a growth in local authority residential

[8] The 1959 Mental Health Act broadly acknowledged the importance of a shift from institutional to community care. Specifically, in relation to learning disabilities disability, it replaced 'deficiency' with 'subnormality' and removed the category 'moral defective' used in the 1913 Act.

[9] See appendix 6.

provision had not been matched by a decline in hospital provision, *Mental Handicap: Progress, Problems and Priorities* (DHSS 1987) was published to accelerate deinstitutionalisation (Stevens 2004, p.240). The recently-formed generic Social Services Departments were set the task of a rapid expansion of standardised models of hostel, day service, together with special school provision by Education Departments.

2.3.1 Interventions

a. Bricks and mortar

Better Services for the Mentally Handicapped resulted in the development of a range of residential and day services, geographically closer to local communities but still separate and segregated provision, relatively large[10] and primarily designed to support parents (Race 2007, p.88). Preparation for work was one objective for these services initially. Later, centres took on contract work; this was repetitive in nature, for which 'trainees' received a small payment each week. 'Workshops' in carpentry, laundries, horticulture and soft furnishings were part of the service structure where staff, who generally had an industrial background, provided technical rather than social care skills (Rooney 2002). The aim was to provide places for all adults, for five days per week (Walmsley 2006, p.88). As contract work began to disappear in the changing economic climate of the 1970's, Adult Training Centres (ATC) became Social Education Centres (SECs) with a broader emphasis on 'education for life', along the lines recommended by the National Development Team for the Mentally Handicapped[11] (Rooney 2002, p.87; Walmsley 2006, p.88).

In 1976 around 50,000 people with learning disabilities lived in large institutions, but 25 years later this had dropped to 4,000 (Emerson and Ramcharan 2010, p.61). In terms of the experience of being a parent of a child with learning disabilities, this could now take

[10] 25 beds, perhaps divided into three units, one of which would provide respite care families as the main carer of a person with learning disabilities. People would have their own room but share a large living/dining room in each unit. Catering and laundry services would be central.
[11] Pamphlet 5 (1977) *Day Services for the Mentally Handicapped.*

several forms. Older parents who had made the decision to place their children in a hospital (having been advised that 'it was best'), and who might have devoted time to voluntary fund-raising to improve the hospital amenities available to that child, were faced with the prospect of change; and, for some, the professional advice that an institution was not the place for their child challenged the validity of difficult decisions made years ago (Race 2002, p.39; Rolfe *et al* 2005, pps.11-28). Other parents, who had successfully campaigned for local services for their children, found their judgement challenged by new thinking that people with severe learning disabilities could live in 'ordinary houses, in ordinary streets'[12]: a simple idea providing the right type of support was available to enable them to do this (Ward 1999, p.x). Other parents, whose children were born in the nineteen seventies[13], accepted education for their children as the 'norm', but then realised that post-18 funding and support could be much more limited. For many parents, policy 'progress' brings new battles and new turmoil, representing a particularly difficult adjustment for older parents who had shouldered the burden of campaigner and arbiter of their sons' or daughters' needs. As the twin policies of 'community care' and 'deinstitutionalisation' unfolded, parents become 'witnesses to change', as changing policy and professional advice influenced their lives (Rolph *et al* 2005).

As 'bricks and mortar' services began to develop in the community, the principles underpinning service models came under scrutiny and concepts were developed which explored the relationships between people with learning disabilities and those who provided their care, as well as their relationships with the wider community.

b. Service concepts

Normalisation

It was the principles of normalisation that became a leading influence on service design for people with learning difficulties from the 1970s (Emerson 1992: Williams 2006;

[12] Kings Fund 1980: see also p.17.
[13] Often with increasing complexity of disability as the science of post-natal care evolved.

McClimens and Richardson 2010). Originating in service planning in Scandinavia in the 1960s (Emerson 1999), it was enhanced and extended into Social Role Valorisation (SRV) by Wolfensberger in America (Walmsley 2001, p.190). He proposed that valued roles be created for groups of people who were seen as devalued; and that the overall image of people could be enhanced through the location of support services, the 'rhythms' or routines followed in those services, and the language and labels used to refer to individuals and services, relationships with others and personal appearance. SRV focuses on creating opportunities for good relations between ordinary people and those at risk of social exclusion (Williams 2006, p.57). Here, in the UK, the King's Fund used the basic principles of normalisation to underpin its extensive blueprint for residential care based on ordinary housing badged as *An Ordinary Life* (Race 2002, p.43: Potts and Fido 1991, p.9).

The beneficial impact of normalisation on the development of 'ordinary life' principles for people with learning disabilities is widely acknowledged but, equally, attention is drawn to its limitations in accommodating diversity and difference (Chappell 1997, p.35; Ward 1999, p.xi). This, all too easily, puts people with a learning disability into a secondary[14] position in a relationship, as well as discouraging (and discounting the value) of friendships and group activities among people with learning disabilities; additionally, normalisation is silent on the impact of economic, social and political constraints on disadvantaged people (Ward 1999, p.x; Walmsley 2006, p.44). The social model of disability emerged as a response to this silence, expounding a philosophical principle to directly challenge the medical model of disability. Proponents forcibly argued that *disability* is not about the bodily *impairments* of the individual but society's failure to understand or meet the needs of the disabled person resulting in social barriers, exclusion and oppression (Oliver 1990). Professionals, particularly the medical profession, managed the problem of disability in a way that cast disability as an

[14] Or dependent.

individual pathology. Oliver[15] describes this perception as a 'personal tragedy theory' where professional support and assessment either 'rehabilitate' people to conform to mainstream society or segregate them into services designed for specific impairments. The social model of disability is welcomed because firstly, it addresses a major weakness of normalisation by its broader analysis of disability which illuminates the role of society in failing to create economic and social environments to accommodate disability; secondly, it challenges the creation of dependency through campaigns for interventions such as direct payments, which offer real alternatives to service-led support. However, a major doubt is raised as to whether it encompasses *intellectual* as well as *physical and sensory disability* (Chappell 1997; 2001, p.46); this echoes a challenge to the underlying principles of the social model from some people with physical impairments (Morris, 1991) around its neglect of impairment and the presentation of a utopian view of a 'barrier free' community (Shakespeare 2006).

Advocacy

In her comprehensive review, Atkinson (1999, p.15) defines advocacy as fundamentally about 'speaking up' from three perspectives: for oneself (self-advocacy); for others (peer advocacy); and citizen advocacy (someone standing up for a person, or by them). Advocacy, at its best, should be based around organisations that are run by disabled people[16], and the support provided should recognise the strengths and individual needs and aspirations of the individual person who carries the label learning difficulties. The origins of advocacy are particularly associated with people with learning difficulties in their relationships with health and social care services (Atkinson 1999, p.9). However, the model of (self) advocacy, which embraces pride in a disabled body or mind, and control of services that goes beyond making choices offered by professional 'others', has not been an option for the majority of people with learning disabilities; real power remains in the hands of professionals and the agencies they represent (Walmsley 2002,

[15] 1993.
[16] Not by non-disabled people – 'semi-professionals'.

p.31; Stevens 2004, p.250). Historically, the crucial claim to humanity, and then a right to have your voice heard, has been in question for people with learning disabilities (Gray and Jackson 2002 p.7), and their whole history 'is not so much theirs as the history of others speaking on their behalf or against them' (Ryan and Thomas 1987, p.85). Although there are many examples of positive work by advocates and people with learning disabilities themselves (Lawton 2007 p.43), citizen advocacy can reflect a relationship in which the person with learning disabilities is dependent upon the skills and interests of others, and where outcomes for them are limited to improving their communication skills and being involved in consultation about the services - as opposed to advocacy incorporating a right to challenge decisions and range of support offered by a local authority (Apsis 1997, p.647). Even since the publication of *Valuing People* (2001), the scope of choice offered to people with learning disabilities, in terms of where they live, and with whom, and which agencies are funded to provide advocacy services, has been determined by Commissioning Managers in statutory agencies (Fryson and Kitson 2007).

2.3.2 Professionals

Deinstitutionalisation and supported living raised challenges in terms of moving staff into new roles with new values and ways of working. Just as Payne (2005, p.33), points to the transfer of Poor Law staff into local authority social work agencies in 1948, so Race (2002 p.43) postulates that professional and employment issues played a significant part in the 'quiet burying' of the Jay Committee Report (1979)[17]; and have continued to influence social policy since then.

14 Whose recommendations closely resemble the principles adopted in *Valuing People* published twenty years later.

The Local Government Act of 1929 brought about the beginnings of a local government social work service, which was enhanced in 1948. In 1968 the 'Seebohm Report' led to the Local Authority (Personal Social Services) Act 1970 (Payne 2005, p.57). Post-Seebohm there was very limited experience of learning disabilities within the newly-unified Social Work Departments (Race 2002, p.39).

2.4 Active Citizenship

NHS and Community Care Act 1990

By the late 1980s an escalating social security bill, as a result of the growth of the private and voluntary residential care market,[18] was of great concern to the Government (Glendinning and Means 2006, p.15). Social policy under a New Right Conservative administration developed an approach which favoured private sector involvement and the 'quasi-market'. Statutory services were split into those purchasing (or commissioning) services and providers to create an 'internal market' stimulated by the development of private sector provision alongside the traditional mixed economy of welfare provided by the state, voluntary and informal sectors. This was seen as a mechanism capable of accommodating multiple individual demands and creating efficiency through competition and supporting innovation; the opposite of an inefficient, unresponsive, state system with poor information systems held to sustain uncompetitive services (Clarke 1998, p.17). These ideas gave birth to a landmark piece of legislation (Walmsley 2006, p.84), the 1990 National Health Service (NHS) and Community Care Act, the Government's response to the 'problem'. While claiming to promote the benefits of community care, it was seen by many as a means of curbing social security expenditure (Brenton and Ungerson 1989, p.145; Means, Richards and Smith 2008, p.51; Walmsley 2006, p.40). The Act gave social services department's responsibility for assessing needs and establishing eligibility for services thus keeping in check the hitherto uncontrolled demands made on social security budgets for private

[18] Including learning disabilities services as private and voluntary increased in numbers as deinstitutionalisation progressed.

residential care. The principle of increased choice was the major justification for the creation of this 'market place' approach. The 1997 Labour Government believed the quasi-market approach to social care had failed (Hudson 1999, p.192), yet their 'modernisation' agenda was underpinned by many of the core policy principles of their Conservative predecessors, particularly the notion of the supremacy of the individual 'consumer citizen' - albeit within an inclusive society.

2.4.1 Interventions

Direct Payments

The 1996 Community Care (Direct Payments) Act heralded a significant new opportunity for a person assessed as eligible for community care support. Instead of dependence on others – often in the form of segregated services – it was possible to be allocated your own budget and choose how to spend it; choice and control over support that could enable individuals to go out visiting, attend meetings or leisure activities, or pay for help with household tasks (Leece and Bornat 2006, p.1). Direct Payments have a stated purpose: *'to give people control over their own life by providing an alternative to social care services provided by a local council' (*Department of Health: 2003). This concept represented a shift from 'fitting' people into traditional services to giving people control through information and/or management of the funding allocated to meet assessed needs; and choosing a much broader range of support services. The 1996 Act[19] was the welcome result of a long campaign by disabled people to challenge dependency and to create opportunities to exercise independence (Leece and Bornat 2006, p.1). Independence, it is suggested, can be defined in a number of ways, but the central concept is for the individual person to be able to exercise choice and control. Positive outcomes such as improved self-esteem, increased control over lives, deeper relationships and new opportunities have been identified (Spandler 2004; Stainton and Boyce 2004; Glasby and Littlechild 2009, p.120). The critical factors to successful

[19] Extended in 2003, and offering a direct payment became a duty upon local authorities under Section 57, Health and Social Care Act 2001.

outcomes learned from the direct payments experience are usefully summarised as: firstly, the approach taken by the local authority to implementation; secondly, staff training and attitudes (Glasby and Littlechild 2009, p.53).

Modernising Social Services

Modernising Social Services (DH, 1998), under a New Labour Government, aimed to address issues of protection, coordination, inflexibility, clarity of role, consistency and inefficiency in the provision of services to all user groups. There was a requirement for partnership working between the main agencies of social care to promote the economic, social and environmental well-being of their areas (Hudson 1999, p.193). An important aspect of the 'modernising agenda' was the move away from organisational issues to a greater concern for 'well-being' and outcomes for staff, service users and informal carers (Newman *et al* 2008, p.535)[20]. The specific intentions for learning disability services appeared in 2001 with the publication of *Valuing People*. A shift in the make-up of learning disability services across 30 years is apparent in a comparison between the White Paper of 1971, *Better Services for the Mentally Handicapped,* and that published in 2001, *Valuing People*[21]. A significant clue lies in title which reflects a focus on 'services' and then, 30 years later, a shift from services for a collective group of citizens to a focus on 'people', in the form of individualised provision for 'consumer' citizens.

2.4.2 Professionals

For social workers working with adults, the 1990 NHS and Community Care Act had a significant impact on their role, with many suggesting social work at that point became determined by managerial direction and governed by tight policies and procedures (Holloway 2009, p.315; Parrott 2010, p.3). Within these constraints social workers could

[20] As opposed to measurements of the processes required to implement policy.
[21] See appendix 6.

find their value base, which aims for empowerment, in conflict with their responsibilities for eligibility criteria and gate keeping publicly-funded services (Ellis 2007, p.410).

As a positive starting point, Care Managers are likely to have made a choice to work with people with learning disabilities (Cree and Davis 2007, p.117), and the interaction that takes place in the relationship between Care Manager and Service User at the point of assessment, and then service planning, should be an empowering one; knowledge is shared and the Care Manager is not an expert, but a facilitator helping individual people (not a category of people) to act autonomously in terms of deciding what they need and want. Here they are supported to make decisions and to have an enhanced ability to act on their choices (Stainton 2009, p.354). One means of providing protection, even in the sensitive area of sexual relationships, can be through access to information and education whereby people have the knowledge needed to carry out their choices; other forms of protection only leave them unprepared when things go wrong (Hollomotz 2011, p.167). The important balance of empowerment and safeguarding should be developed around a framework of interdependency rather independence.

2.5 Learning Disabilities in the 21st Century

Valuing People

Valuing People (2001) is based on a principle of promoting independence. It centres not so much on specific services, but on the 'themes' that should underpin them. These include 'choice and control', 'supporting carers', 'health' and 'housing' (Race 2007, p.95). *Valuing People* represented a major shift in government policy-making in that it was developed by working parties that actively involved both service users and carers. Post publication that involvement continued through the National Forum for People with Learning Disabilities and the National Learning Disability Task Force. With the former, regional service users forums, made up of representatives from local advocacy groups, provided links with policy makers; the latter was a body established to oversee implementation of the White Paper (Fyson and Ward 2004, p.1).

At a local level, people with learning disabilities, and carers, were to be full participants in local Learning Disability Partnership Boards, an inter-agency structure expected to deliver strategic plans as a catalyst for change in local services. Lead responsibility lay with the local council (HSC2001/06: LAC [2001]23; October 2001). Other members included not only representation from learning disability specialist services, but also agencies responsible for housing, education, leisure and employment. It went beyond specialist statutory services seeking to engage the contribution of a wider community network of citizens (Fyson and Ward 2004, p.19; Burton and Kagan 2006, 209-313).

A key instrument for planning at the level of an individual person with learning disabilities was to be person-centred planning (PCP) which aims both to consider the aspirations of the individual (as opposed to needs and deficiencies) and then to include the individual's family and wider social network; and finally to provide services to meet those needs rather than confining plans to service provision (Mansell and Beadle Brown 2004, p.2). PCP enables people to move beyond planning systems solely based on professional assumptions about need, linked in turn to service-led responses that can dominate 'traditional' care management assessment. Care management, informed by PCP, provides a more holistic picture of the individual led by the views and aspirations of that person, particularly if individualised funding is used (at that time Direct Payments) as an important means of enhancing choice and control (Duffy and Sanderson 2005, p.38).

Commentary on past twelve years of *Valuing People,* by academics close to learning disabilities, includes important positives: not least, as already noted, the innovation of user involvement; and Fyson and Simons suggest that *Valuing People* represents a bold ideology addressed to a wide audience (2003, p.154). Additionally, the principles of *Valuing People* (2001) are viewed by the majority of families and professionals as the model for people's lives and support systems (Greig 2008), and those principles are perceived as having an impact on government responses when issues concerning people

with learning disabilities arise (Mansell 2008, p.12). A major concern emerged regarding weak implementation, however, as a result of which *Valuing* People (2001) was seen as a reality only for a few (Walmsley 2006, p.2). A more radical critique of *Valuing People* is rooted in a concern that the principles are not underpinned by new civil rights. Rather the ethos of *Valuing People* (also applied to the subsequent 'personalisation agenda') is seen as part of the culture of 'New Public Management' (NPM) approach to emerge with care management which relied upon a market-led consumerist approach (transferring responsibility from the state to the individual) to social welfare (Cumella 2008, p.178; Ferguson 2007, p.387).

Empirical Research and Reports: Valuing People

Valuing People Now, published in early 2009, was a major review which, although published by the Department of Health, was based on a consultation exercise. This document is seen as keeping alive the principles of *Valuing People* (Williams and Evans 2013, p.37). It claims considerable progress in the lives of people with learning disabilities since 2001 but then uses words such as 'some', 'a few more', and a 'few examples' to talk about the numbers of people and their access to paid work, health action plans, and access to tenancies or home ownership (*Valuing People Now* 2009). The document does concede that for some groups of people - the more profoundly disabled; people from ethnic minorities; those on the autistic spectrum; offenders - considerably more needs to be done. This is seen as an acknowledgement that PCP had not achieved its original goal of becoming central to practice, while reductions in services were leading people to fear that the real driver behind individual budgets was cost-cutting (Condon 2008). Concerns dating back to 2004, it appeared, had not been adequately addressed.

Rob Grieg (National Director for Learning Disabilities 2001-2008) states that *Valuing People's* core agenda was to deliver cultural change, including ensuring the voices of people with learning disabilities and carers are heard. *Valuing People Now* (2009) has a

core agenda of government action to deliver objectives (Grieg 2012, p.12). If that was the intention then it has a major weakness in that it does not set targets, or commit resources, that many would consider to be part of a successful 'delivery plan' (Williams and Evans 2013, p.37).

(1) Learning Disability Partnership Boards

Learning Disability Partnership Boards (LDPBs) evolved very quickly; the 'Strategies for Change' interim report[22] (2004) reveals a central government-driven agenda with timescales that did not allow time to adequately prepare people with learning disabilities with the skills required to make an effective contribution. While JIP's (Joint investment Plans produced by LDPBs) did not reject *Valuing People's* core principles, however, there were limited references to developing these principles within a social model of disability linked to authorities' eligibility criteria. Data about existing people with learning disabilities and their needs are described as 'patchy', and only 10% of JIPs were available in an accessible version (Fyson and Simons 2003, p.154). Subsequently, given their lack of statutory powers, commentators question the link between LDPBs and decision making with respect to money and other resources (Fyson and Ward 2004, p.20). It is suggested that partnerships between citizen and public services are built on assumptions that both share the same view about solutions and outcomes, resulting in control remaining in the hands of professionals and, overall, an underlying 'lack of trust' over the allocation of resources (Riddington *et al* 2007, p.650[23]). In this context, LDPBs can be perceived as involved in the transmission of superficial information or feedback; a harsher perception is that partnership boards exist to legitimise policies dictated from the centre (Cumella 2008, p.178). As might be anticipated from its title, *Making Valuing People Work* provides a series of checklists (to improve the existing process), guiding

[22] Findings were based on an examination of Joint investment Plans (JIP's) from 104 Partnership Boards (LDPB's), 51% response rate to a postal survey, studies of the operation of ten of those LDPB's, then interviews with Commissioners, LDPB Chairs, and carers in twenty local authorities.
[23] Findings based on research in three counties.

LDPBs to clarify their role and responsibilities; develop representative processes; and allow the voice of people with learning disabilities to be heard in an organised and transparent way (Fyson and Ward 2004).

Two other surveys, also published in 2004, raised concerns about LDPBs and their ability to address the needs of all people with a learning disability. Mencap's survey (2004), particularly, highlights the absence of representation for people with profound and multiple disabilities (as did 'Strategies for Change'); while Hatton's report (2004) questioned whether LDPBs were adequately planning to meet the needs of people from ethnic minorities. Similar findings emerged from a further report in 2008[24]. As a final thought, Race (2007, p.97) ponders the difficulties that might face a wide range of people brought together in a 'Partnership Board to deliver consistent and tangible outcomes across complex, and themed, subject areas'

(2) Person-centred planning

PCP is central to the strategy outlined in *Valuing People* (2001), and re-emphasised in *Valuing People Now* (2009), although academic reviews of PCP since the original strategy suggest weaknesses in relation to actual outcomes[25]. They indicate that people's experience of interventions is influenced by the nature of the existing resource; its intended outcomes; and capacity to deliver. In reality, any local authority is presented with major resource and logistical challenges, given the numbers of people with learning disabilities they are responsible for, the range of impairment, and the required involvement of the person's family and social networks. The exercise often results in an acceptable number of PCP meetings completed, but doubts about the quality of the outcomes (Mansell and Beadle Brown 2004, p.4). Staff with the appropriate skills are also seen key to outcomes; particularly the availability of skilled meeting facilitators capable of identifying the aspirations of the people with learning

[24] a Mencap/Learning Disability Task Force commissioned report.
[25] Which *Valuing People Now* does not specify weakness, or offer remedies, referring rather vaguely to the importance of 'best practice'.

disabilities out of all the views and problems that might be expressed by others in the meeting (Robertson *et al* 2007[26]).

In their critical review of person-centred planning, Mansell and Beadle Brown (2004, p.2) argue that whilst there was quantitative evidence of planning (the number taking place), the evidence of results or 'person-centred action' was limited. The authors' conclusion was that lack of action could be explained by failure to change power relations (between professionals and service users), which, in turn, may be attributed to a lack of adequate staff training and supervision, as well as 'system failures'. Other authors, in the same journal issue, acknowledge the concerns raised by Mansell and Beadle Brown but argue that person-centred planning and person-centred action are linked concepts rather than alternatives, and that there should be more optimism about the principles of *Valuing People* (2001) to deliver on person-centred planning.

Self directed support and Personal budgets

The concept of personal budgets began life in 2003 as part of the search to deliver greater choice and control for service users. A small group of people experienced in working in the field of learning disabilities were convinced that a major block to innovation related to the large proportion of learning disability budgets allocated to the ongoing costs (plus inflation increases) of existing buildings and services (Glasby and Littlechild 2009, p.77). This led to In Control, a project aimed at developing alternative ideas for organising social care. In Control created the concept of self-directed support: having services ready for use that matched people's needs rather than people having to slot into services on offer; people needing support choosing who provides it, and being in control of when and where either services and/or support is provided (Glasby and Littlechild 2009, p.13). Self directed support logically led to the concept of individual budgets (Gardner 2011, p. 11). By 2007 In Control was working with 17 local authorities

[26] Robertson *et al* 'Person-centred planning; factors associated with successful outcomes for people with intellectual disabilities: a two year study of 96 adults.

and 196 service users in developing models of self-directed support and individual budgets. Their evaluation was made up of 58% participants with learning disabilities, 20% physical disabilities and the remaining 13% were older people[27]. The evaluation also acknowledges that it had limitations in terms of representativeness (p.23) but indicates that people with learning disabilities reported improvements in quality of life together with greater choice and control (Glasby and Littlechild 2009, p.95).

In 2005 a development from the Department of Health's adult social care Green paper, *Independence, Well-being and Choice*, recommended the creation of pilot studies to develop an evidence base. Thirteen such pilots were established, across a range of local authorities and all social care groups. What was to become known as the IBSEN evaluation also had an agenda to explore the integration of range of social care budgets, a more complex picture than the In Control evaluation of self-directed support (Glasby and Littlechild 2009, p.81; Gardner 2011, p.59). IBSEN identified mixed results for people with learning disabilities involved in the pilots; crucially people with learning disabilities were more likely to feel they had control over their daily lives as a result of an individual budget, perhaps because more opportunity was available for leisure and social participation. Whilst it is suggested that people with learning disabilities may have benefited from previous experience of PCP and an inclusive approach[28], they also reported frustration with the time taken to get budgets and supports established. IBSEN also identified the major structural hindrances to integrating budgets from differing sources around an individual person (Glasby and Littlechild 2009, p.97; Gardner 2011, p.60). The different principles underlying the two projects[29] suggest that some caution, as well as some optimism, is required in their interpretation (Gardner 2011, p.58). Experience additionally suggests that whilst pilots are helpful, other impediments would

[27] Because they did not receive information from all participants those percentages do not total 100% of the 196 (Hatton and Walters 2008, p.9).
[28] Person-centred planning has been part of learning disability models of working for some years.
[29] In Control aimed to evaluate the experience of self directed support; The IBSEN study was also taking account of the integration of different funding streams with social care budgets.

be identified in a national implementation, both because of size and complexity and because pilots tend to comprise keen advocates of their ideology (Gardner 2011, p.58).

Safeguarding

The reports on the 13 Individual Budget pilot projects also highlighted a concern about the risks that accompany new ideas and the exclusion of those with knowledge and experience of adult protection from planning and oversight of the pilot projects (Manthorpe *et al* 2009, p.1477). These latter concerns focus around the new lifestyles people on individual budgets might adopt; no longer dependent upon services, but purchasing supports for themselves and possibly employing support staff. Whilst enjoying choice and independence, outside of regulated services, they could be the victims of financial abuse. Prior to this, Walmsley (2006, p.6) had warned of the dangers of people's needs being minimised, resulting in experiences of poverty, petty crime and bullying (Emerson and Hatton 2004). Safeguarding, and the extent to which people with learning disabilities were vulnerable when 'living in the community', rightly became a major discussion point. The failure to accommodate or recognise the needs of people with learning disabilities has also proved to be an issue for mainstream agencies and the services they commission or provide. The 'Independent inquiry into access to healthcare for people with learning disabilities', chaired by Sir Jonathon Michael, found that people with learning disabilities encountered significantly more difficulties in accessing assessment and treatment for general health problems that were not directly related to their disability and required health professionals to make reasonable adjustments to support the delivery of equal treatment, as required by Disability Discrimination Act (Inquiry Report 2008, p.7). The report into the Cornwall Partnership NHS Trust (Independent, 5 July 2006), and events involving Sutton and Merton Primary Care Trust between 2002 and 2005 (Community Care, 17 January 2007) and, later, a Department of Health Review in response to the Winterbourne Hospital (2012), all demonstrated the challenges of providing effective safe services, particularly for those with complex needs and/or challenging behaviour and ensuring people are not lacking in the valuable

relationships with families, friends and professionals that can be a prime deterrent against isolation and abuse.

Personalisation

The underlying principle of personalisation - focussing on the individual person, encouraging choice and control – emerged in 2007, under New Labour, arguably as a development of *Valuing People* (2001). It fits with its aspirations of *Valuing People* to view the person as an individual as opposed to being a member of a homogeneous group carrying the label of learning disability. In 2010 there was a change of Government and (before the end of its three-year life) *the Valuing People Now* team: its national directors and nine regional leads were axed as part of the incoming government's spending cuts (Community Care, July 13 2010). In 2012, uncertainty existed around the coalition government's intentions, and whether the *Health and Social Care Bill* 2012[30] would be compatible with the principles of *Valuing* People and the objectives of *Valuing People Now.* Under a Conservative-led Government, personalisation has become a cross cutting agenda (Needham 2011, p.550). Fears are expressed for the needs of people with learning disabilities if individualised approaches threaten collective activity, such as advocacy, or the joint activities and specialist support that some people with learning disabilities draw benefit from at particular points in their life journey (Walmsley 2011). A more radical challenge, applied to the entire social care field, is that increased user choice is a mask for an objective which allows the state to withdraw support for the welfare state that has developed post 1945 and weakens the collective action that has been part of social care in learning disabilities and mental health for many years (Ferguson 2007, p.401).

[30] Now legislation (July 2013)

The future

The principles of *Valuing People* (2001) and the statements expressed in *Valuing People Now* (2009) make a strong link (*Valuing People Now* 2009, p.53) to the concept of 'transforming services to make them more personalised to the needs of the individual user'- an agenda that remains a key part of social care policy in 2012. The life chances for people with learning disabilities, alongside their own personal drive and aspiration, will be closely connected to the relationships they experience with others, both at a wider planning level (Partnership Boards) and at a personal level in their day to day interactions, including 'formal' person- centred planning meetings.

Summing up the issues that have been part of the learning (in 2004)[31], since the inception of *Valuing People* (2001), *Making Valuing People Work* highlights the foundations of any process if people with learning disabilities are to be valued: putting them first; adequate time for learning and development; and transparency in operation. People with learning disabilities (not unlike everyone else) need both time and training if they are to develop new skills. Representing the views of others, taking on board new information and disseminating it to others, involves new skills and challenges, particularly so when a facet of a disability may be difficulties in reading and assimilating written words and complex concepts. Local authorities should think carefully about their processes of consultation, involvement and decision making, making it clear what is possible and where final responsibility may lie if it is outside the constituted group[32]. Fully including people with learning disabilities is essential, but to do it is a complex, multidimensional task which should be transparent in all its stages.

The issues discussed in this literature review underpin the choices made with regard to the methodological approach adopted to the research, which are discussed next.

[31] *Valuing People Now* (2009) findings suggest the lessons were not learnt.

[32] For example a Partnership Board may be discussing an issue and making recommendations, but the final decisions may lie elsewhere with the formal authority vested in a meeting of the Council.

3. Methodology

3.1 Introduction

Ontology, epistemology and methodology are interrelated, with ontology the starting point of all research from which epistemological and methodological positions logically follow. Grix (2004, p.60), stresses that our ontological position, whether we are aware of it or not, is implicit even before a topic of study is chosen. My personal approach as a researcher is based on an ontological perspective of constructivism which contends that social occurrences and their meaning develop from ongoing social interaction between people; there is no one definitive account, rather a constant revision, and the research task is to *understand* social occurrences as opposed to *explaining* them (Bryman 2008, p.19; Grix 2004, p.53).

For this researcher, social work training and thirty two years' working experience have been based on recognising the individual person and their potential for development and independent action. Those same experiences, particularly an involvement in implementing the changes advocated and required by *Valuing People* (2001) in the latter part of that career, as a service manager, demonstrated the institutional constraints for people with a learning disability that have been created over time, including the difficulties of moving from specialised, segregated services to mainstream community options. This experience, and the perceptions which stem from it, have

influenced the selection and approach of this particular research. It has the advantage of the researcher being known to both groups of participants – which helped to secure access – as well as providing some understanding of the issues presented. At the same time, it is recognised that these same insights could act as a barrier if they drew on preconceived ideas or even power over the participants. Steps were therefore taken to ameliorate this through the use of advocates in the field work, and the sharing of interpretations between researcher and study supervisor through the submission of written drafts, journal records and discussion in supervisory sessions.

3.2 Methodology

My epistemological perspective is one of interpretivism based on the assertion that there is a logical relationship between ontology and epistemology (Grix 2004, p.59). An interpretive approach acknowledges subjectivity, based on the belief that the social sciences, concerned with people and their institutions, requires a perspective that recognises the particular attributes of humans, as opposed to the 'order' of the natural sciences (Blaike 1993, p.36). Using such a perspective, it is hoped to draw out understandings of concepts such as 'independence' by a particular group of people with learning disabilities; to acknowledge the potential for difference, and individual nuances, in aspirations between people who may bear the collective label of learning disability. Therefore this research explores the benefits of a contextual study (Bryman 2008, p.397), which seeks to illuminate the particular (Lincoln & Guba 1985) by accessing the interpretations of one, local group of people with learning disabilities.

Qualitative approach

In terms of a research method a qualitative method was adopted to fit with the chosen methodological approach. Therefore, my research will be a micro-level orientation which is described as a *'focus on social interaction in a specific situation'* (Macionis & Plummer 2005, p28). This form of research is based on the researcher looking at a 'small scale' situation in its social and cultural context (Grix 2001, p.33).

The strength of *Valuing People* (2001) was that its key principles[33] set out to challenge service models which have been a straightjacket to people with learning disabilities, and to create a vision of both independence and choice which offered people 'a real say' in their life choices (Race 2007, p.89). The researcher, however, would argue that options of independence, work and leisure are generalisations; intellectual disability[34] may require particular forms of support (Walmsley 2011), and not all people with learning disabilities will aspire to them in exactly the same way. As an example, some of the wider social benefits of work might be achieved by the contribution of voluntary work. Whilst learning disability does have common characteristics, the people who carry that label are a diverse group (Bigby & Frawley 2010, p.2), and, it can be argued, a propensity to see them as a homogeneous group has been a major limitation on individual aspirations.

For many connected with academic study, only research that can be generalised to a wider population has both validity and enduring value (Lincoln and Guba 1985, p.111; Denzin and Lincoln 2003, p.69). Lincoln and Guba go on to note that generalisation fits with political processes, whilst highlighting the dangers of a simple 'reductionism' which reduces all phenomena to a single set of generalisations (p.117). *Valuing People Now* (2009) portrays a picture of limited success in achieving fully the principles of *Valuing People* (2001) in the daily lives of people with learning disabilities, but this too may have the limitations of a generalised picture.

This qualitative research method provides an in-depth view of a complex social situation, using thick description (Geertz 1973, p.6), and offers the possibility of alternative explanations to the issues people with learning disabilities face (Denscombe 2010, p.304). The insights gained will have local application, but also provide other researchers with concepts they may wish to test through interactions with people with

[33] Rights, Independence, Choice and Inclusion.
[34] As opposed to physical and sensory disability.

learning disabilities. This research will also aim to suggest methods – other than sole reliance on verbal and written communication - which capture the interpretations and expression used by people with learning disabilities, a group of people who are particularly challenged to understand and respond to contributions based entirely on conventional conversation and dense written text.

Having selected an approach, careful thought is required concerning the importance of the standards required for any research method. Bryman is one writer on research methods who makes reference to the debate about the benchmark of scientific research being based on standards of reliability, replication and validity, and a view that these are more clearly associated with quantitative methodologies and the study of the natural sciences (2008, p. 376). There is some recognition that a simple transfer of quality measures for quantitative research to qualitative research is not possible (Bryman 2008, p.383). Silverman (2005) also makes the point that both 'quantitative' and 'qualitative' research can be found to have limitations – awareness of any limitations, and plans within a methodology to address them, are important to achieving the best possible outcomes in meeting validity and replication of the interpretations reached in the research.

Bryman (2008, p.376) also points out that replication (as a measure of external reliability) is challenged by the impossibility of freezing a social setting that is the subject of qualitative research; any small study cannot meet a test of validity based its ability to be generalised to a wider population. In opting for a qualitative approach to the research question, the researcher has noted, in designing the methodology, Grix's summary (2004, p.121) of the key criticisms of a qualitative approach. These are questions about whether small groups are truly representative, weaknesses in being able to generalise from such small samples and what Grix calls the 'immersion' of the researcher into the social context of the study which then raises questions of the researcher's 'objectivity'. The importance of ensuring a balance between detailed

description of the situation, and an analysis that can order and summarise the issues, is also made (Lofland and Lofland 1995). The question of interpretation brings up the issue of individuals defining things in different ways. An example is a homeless person on a city street who will be seen by some passersby as a scrounger, and by others as a person in need (Macionis and Plummer 2005, p.28). Additionally, interpretation of social entities itself affects the outcomes from them, thus it also has to be acknowledged that researchers are not detached totally from their chosen research. Rather they add their interpretations to the interpretations of the social actors involved: the concept of 'double' interpretation (Bryman 2008, p.17).

Alternative quality measures – namely trustworthiness and authenticity - are suggested as more applicable to assessing qualitative research (Lincoln and Guba 1985; Bryman 2008, p. 378). Trustworthiness requires an assessment of the researcher's good practice in not allowing personal values to sway the research, and using thick description to portray the context of the research. Being able to audit the conduct of the research and check the write up of group sessions with participants[35] provides a measure of credibility and dependability. Authenticity is a measure of whether the research represents a fair analysis of differing viewpoints whilst supporting people to understand their social situation and the perspectives of others, together with providing them with an impetus for action (Bryman 2008, p.379). The emphasis on practical outcomes suggested by the authenticity criteria has not been popular in social research (Bryman 2008, 377), although the work of Yardley (2000), as one example, suggests it is applicable to practice in the field of health education. In relation to authenticity as part of the overall aim of transparency, this research seeks to describe methods which enable people with learning disabilities to remain in control of the key decisions in their lives, but be supported in areas of information provision, together with recording of discussions and decision-making in ways that are not totally dependent upon complex verbal and written skills. Thus, the research can meet the authenticity criteria through

[35] Respondent Validation (Bryman 2008, p.377).

achieving impact and significance for both theory and practice. A key part of authenticity is the researcher's reflexivity in considering fairness in representing different viewpoints that emerge from the research (Bryman 2008, p.380).

Participants

An important part of the requirement for transparency in any research (Bryman 2008, p.392) is clarity about the participants and their selection. Central to this specific research are the stories of six people with learning disabilities who participated in the first of three focus groups. The six were selected on the basis of their membership of a group, Right Track, who had negotiated with their local authority a role in helping to provide people with learning disabilities with information about the opportunities associated with direct payments and, later, the personalisation agenda. The group is small in number and represent particular age groups (40 to 68). None are representative of either profound impairment or of people from ethnic minorities, although their work with Right Track brings them into contact with many other people with learning disabilities. Ten Care Managers[36] – social workers and nurses - from the local authority Social Services Adults with Learning Disabilities Team participated in the second focus group. A third focus group was a joint one comprising some people with learning disabilities from Focus Group One and some professionals from Focus Group Two.

This then is a small-scale social research project focussing on the particular (Denscombe 2010, p.62), seeking to understand the subtleties and intricacies of people with learning disabilities' aspirations and their expectations of professional support. The researcher's current role with Right Track, held since 2006, and preceded by 27 years in the field of learning disabilities within the local social services department, guided the selection of the participants[37] (Silverman 2005, p.15), and is an acknowledged influence throughout the process of the research. A pragmatic selection of participants of this type aligns to a non probability form of sampling. While it does not lend itself to generalisations across a

[36] After preliminary negotiations to undertake the research no managers were present at any stage of the research.

[37] Accessibility to both people with learning disabilities and professionals.

wider population, sometimes a unique situation may be representative of a broader situation (Bryman 2008, p.415; Denscombe 2010, p.60). This research throws a spotlight on one group of people who have been part of the national development of learning disabilities services; its context is a small group of people who operate in a specific environment (Bryman 2008, p.397). Its prime intention is: firstly, to support Right Track members with their aims[38] and, secondly, to have impact and usefulness in a local situation, reflecting an increasing interest in small-scale studies which are sensitive to context and participants' perspectives (Yardley 2000, p.219; Porter and Lacey 2005, p.103).

Ethics

The ethical principles of social research can be considered under four main headings (Bryman 2008, p.118):

i. the prevention of harm to participants;
ii. ensuring informed consent has been obtained;
iii. maintaining confidentiality;
iv. ensuring the research methods involve no deception of participants.

This research acknowledged the possible vulnerability of people with learning disabilities because of their intellectual impairment, but also wished to explore the potential for them to consent, make decisions and exercise choice in a way that enhances their opportunities for full citizenship. The second group of people consisted of members of a social work team who have professional responsibilities to support people with learning disabilities to access resources such as direct payments. In the process of obtaining informed consent from both groups, the intention was to treat each equally by giving a verbal and written explanation of the research aims and

[38] Providing support to people with a learning disability to access clear and accurate information about personalisation and other changes in social care (see appendix 2 for more detail).

objectives, and what their participation would mean. The established principle of 'informed choice' for people with learning disabilities was applied to their consent by providing an 'easy read version' of all written material together with advocate support in understanding the nature of the research and their participation. The use of advocates was also designed to help ensure that the researcher's previous roles, and people's perceptions of this role, did not exert an undue influence. Advocates were briefed to be vigilant for any signs of stress amongst participants and to be available for support for a period, if needed, after the Focus Groups finished. The use of venues and ground rules for meetings were based on those already used by people with learning disabilities in the County, so as to provide some familiarity, and militate against stress; and allow them to travel to meetings independently, using public transport[39].

Confidentiality was to be assured by not directly identifying any participant in the final report, but participants were warned (as included in the ethical approval form agreed by the University) that anonymity could not be guaranteed as they belonged to group with a high profile in the local area. All data was password protected on computer, and paper data stored in a locked cupboard. Later people with learning disabilities challenged the position of confidentiality, saying they wanted to be identified with the results of the research. In particular they wanted their photographs in the Viva presentation so people would understand it was about their lives, and that the work of Right Track 'belongs' to them. Compromises were made in this situation, but any future work would ethically need to consider the balance between confidentiality and acknowledging the contribution of people with learning disabilities at the outset.

Summaries of transcripts of group sessions were offered to participants so that amendments due to factual inaccuracies could be highlighted and discussed. The thesis will acknowledge any differing interpretations of the groups and a clear explanation of why the researcher has chosen a particular interpretation.

[39] See appendix 3 for full details and format of the information provided.

Information was provided to the University of Bedfordshire, and the responsible local authority, explaining the nature and intentions of the research; both approved the research and its ethical approach. The researcher also met the registration requirements for the Health and Care Professions Council (HCPC), and local authority requirements in relation to enhanced disclosure.

Insider Research

The researcher's previous role as a Service Manager responsible for the local authority services (three participants currently receive services, three did in the past) supporting the participants, and current role as a 'supporter' to Right Track, placed the research within the boundaries of the University's guidance on Insider Research (IASREC, October 2009). The research did take place after retirement from the local authority, and by 2012 (when the research was being written up) the researcher had been retired over six years. By this time Right Track had evolved into a Community Interest Company with two people with learning disabilities in the formal roles of Company Directors. Whilst acknowledging the potential for a power imbalance in the researcher-researched relationship given the researcher's role as a non-disabled advisor working with Right Track, this was balanced by the formal role of two focus group participants as Directors of Right Track, and the experience of the other 'supporters', who assisted in the conduct of the Focus Group and who had a proven track record in advocating for the rights of people with learning disabilities.

The researcher has no hesitation in acknowledging friendship with the people with learning disabilities who participated in the research. This relationship, together with connections with the local authority concerned, eased access to participants. It was a pragmatic approach where the prior links with Right Track helped to build rapport and an awareness of people's needs in terms of venues and group work methods with which they were comfortable. This also involved linking them to advocates. This approach was,

in the researcher's opinion, one means of empowering participants to contribute in a meaningful way, as well as enabling informal monitoring of their needs for support after the Focus Groups had been completed. The researcher does not claim personal experience of bearing the learning disability label, or service user experience associated with that label. That is the unique and very valuable contribution of participants in Focus Group One as part of a story they may struggle to get heard. The researcher acknowledges his responsibility for reliability and credibility in the writing up of the research outcomes; the aim is analytical objectivity (Blythe *et al* 2013, p.11), but it is acknowledged that this will be a partial account of the participants' lives, influenced by the original intentions of the research.

3.3 Methods

Literature Review

The main focus of the literature search was the ESBCO-host databases available in the University's Learning Resources Centre to identify indexes, abstracts and catalogues taking the systematic approach suggested by Hart (2006, p.22). References in the sources captured in the original search were, where relevant, followed up to support understanding of the points being made. As a novice, the researcher lacked the capacity for a full systematic review but was mindful of the important standards it sets. He acknowledges the support of his study supervisor in planning the literature search and supervisory discussions ensured an ongoing reflexive process throughout the research process (Bryman 2008, p.91; Grix 2004, p.45). Only peer reviewed journals were used. The time period was limited to 1997-2008; the rationale for this was it covered the period of social policy in which *Valuing People* was developed and published. Later an extension to 2009 allowed the inclusion of the important review, *Valuing People Now,* published in early 2009, and the publication of the evaluation of the Individual Budget Pilot programme (Glendinning *et al* 2008); this was a natural extension of the direct payments mechanism which impacted on the themes of choice and control. The Secondly, the review was confined to UK-based sources, as these provided the

geographically and culturally relevant setting for *Valuing People* as well as the experiences of the researcher and participants. Thirdly, the research was limited to adults with learning disabilities although there are references to educational approaches to learning disabilities where they have some bearing on the issues adults face.

The literature searches were based on three themes. The word *learning* was used firstly in conjunction with the word *disabilities* to capture the term favoured by government-based literature, and then *learning* and *difficulties* to capture literature associated with the social model of disability (Race 2002, p.3). The term *'intellectual disability'*, principally associated with American terminology, was also used as it finds usage in UK psychology literature. Understandings of the important historical development of learning disability were based mainly on the works of Mathew Thompson (1997), David Race (2002) Welshman and Walmsley (2006) and Atherton 2007, although cross-referenced to journal articles and to reviews of the books themselves.

Fieldwork: Focus Groups

The fieldwork stage of the research is based on the focus group method (Bryman 2008, p.473), which is one method that fits with a qualitative approach to research. Focus groups have been a feature of market research methods for a long time, and have relatively recently been used in social research (Flick 2008, p.xvi). Group interviews seek the views of the group members on a range of subjects, but the variation of a focus group model has two particular benefits. Firstly, it can have an emphasis on a identified topic; secondly, interactions between group members is a positive element, that is, people's views on the subject can be heard but the individual's views can be interrogated by other members of the group, allowing the facilitator to see how views might be moderated, or new ideas picked up by an individual in the group as a result of points made by others (Bryman 2008, p.473). This approach was chosen for its potential to identify a range of views on this topic, either by people with learning disabilities or

the professionals, avoiding the possibility of assuming there is 'one' view representing the position of people with learning disabilities or professionals.

The researcher's role is described as facilitating rather than leading the group interaction (Denscombe 2010, p.176), which can present three main challenges. Firstly, groups can be difficult to control in the sense that the researcher may be taken away from the key themes of his research; secondly, one or two people speaking at the same time can cause problems in transcription; finally, 'group effects' may impact on the less confident, who may not express views that appear contrary to viewpoints already expressed by more confident group members (Bryman 2008, p.488). These themes will be discussed in the next two chapters.

Three Focus Groups were planned to explore participants' views, as follows:

(1) Members of Right Track: to explore the aspirations of people with learning disabilities for their own lives, how direct payments might support these aspirations and their views on the nature of interaction with professional people required to use Direct Payments to achieve their aspirations;

(2) Adults with Learning Disabilities Social Work Team: using parallel questions, to seek professionals' views on people with learning disabilities' aspirations for their own lives, how direct payments might support these aspirations and how they see their interaction and role with people with learning disabilities in this context.

(3) A joint Focus Group: to use role-plays of Care Managers and people with learning disabilities undertaking an assessment for a direct payment as a means of developing a dialogue on aspirations and models of support.

Given the aim of this research, it was important that the methods balanced an appreciation of people with learning disabilities' particular needs for support with

recognition of their ability and aspirations in respect of choice and control in their daily lives. Just as this was a consideration in the methods used to provide people with information when introducing the research, it also applied to fieldwork methods. For some people with learning disabilities, language may not be their primary source of expression; neither is reading a lengthy document likely to be the best preparation of recording their views.

To ensure methods were consistent with people's communication proficiency, the following methods were used. Firstly, all sessions were audio recorded (and notes were also made during each session), and the tapes transcribed by the researcher. Visual recording was considered but rejected on the grounds that it might be intrusive and would have required skills not previously used by the researcher. Group participants received a copy of the analysis written up from
the transcripts and were asked to return any comments to the researcher. In the event none of the Care Managers responded with any comments; this may have been time pressures, but it is perhaps also reasonable to assume there were no glaring misinterpretations that they wished to correct. In the case of people with learning disabilities, a summary of the key points from the Focus Group discussion was prepared then discussed with participants. The pictorial record[40] they had made during the first Focus Group to record their life experiences and 'history' was revisited to ensure it clearly recorded what participants wanted to say.

In the next two chapters the findings from the three Focus Groups and the analysis of those findings is presented. An awareness of the actual impact of the researcher[41], and then his fairness in representing different viewpoints of all participants, is an important consideration in all three focus groups. The effectiveness of the activities used to help people with learning disabilities express their views in Focus Group Two is also

[40] See pp's 51, 58-59, 63-64, 70-72, 76-78, 82, 85.
[41] This includes past experiences and role as well as facilitation of the groups.

important; these aspects will have a bearing on the impact of the research and its value in supporting participants (service users and practitioners) in the future.

A Note:

The next Chapter (Findings) covers the discussions which took place in three Focus Groups. The first one was Right Track members (people with learning disabilities). The second Focus Group compromised of members of the local Adult Learning Disability Team, and the third Focus Group was a joint one; some people with learning disabilities from Focus Group One, and some professionals from Focus Group Three.

In the two Focus Groups where people with learning disabilities were participants graphics were used to as an additional means of assisting them to record their contributions and to provide a record that was meaningful to them.

The three graphics 'timelines of community care' illustrate the lives of five people with learning disabilities against the background of social care policy of the last 30 years.

4. Findings

4.1 Introduction

For the reasons outlined in my chapter on methodology, I chose Focus Groups as the main approach for my fieldwork. Three successive Focus Groups were undertaken in March, April and June 2012. The starting point was to work with six people with learning disabilities (Focus Group 1), taking the key themes from the literature search[42] to explore with them:

1. How did they think they were perceived by others, and how did they want to be seen?

[42] See appendix 4.

2. Their experiences of 'community care services'.
3. Their view of the impact of *Valuing People* on their lives, in particular their experiences of exercising choice and control;

The topic guide for the Care Managers (Focus Group Two) consisted of parallel questions aimed at exploring their perceptions of people with learning disabilities and their professional relationship with them in the context of community care. The third Focus Group was a joint one, four people with learning disabilities and two professionals[43] from the Adult Learning Disability Team, designed to explore how the individual with learning disabilities and the professional perceive direct payments, and interact with each other in assessing whether this is a means for the former to achieve his or her aspirations and/or how a direct payment might be used as a starting point to an aspiration for more choice and control in the person's life.

4.2 Perceptions of people with learning disabilities

In Focus Group 1, the perceptions of people with learning disabilities[44] were initially explored through an activity called the 'Relationship Map'. A large sheet of paper pinned to the wall had a graphic at the centre which represented the Focus Group member. The sheet was divided into 4 sectors: (1) Family; (2) Work, day services and college; (3) Paid staff or supporters; (4) Friends and people who are not paid.

Each member of the Focus Group had a set of graphics[45], with their code number on it, to represent people in their lives. The task for the person with learning disabilities was to name key people in his or her life, then place the labelled graphic on the sheet in one

[43] For the third Focus Group two people with learning disabilities said they were unable to attend. Only two Care Managers could be released because of leave and work commitments within the team. This compromise was negotiated on the afternoon of the day before the Third Focus Group.
[44] Six people with learning disabilities participated in Focus Group One.
[45] The graphic represented a person and had the participant's unique code number it. Participants could then write on it a relationship (parents, brother friend etc) and then place it in one of the concentric circles.

of the four sectors. The sectors also facilitated identifying the closeness or importance of the relationship through three circles extending outwards.

See Graphic over the page

Fig A: The Relationship Map

The graphic in the centre of Fig 1 represents the person; the circles nearest the centre their identified closest and most important relationships. When the completed graphic was discussed, the largest collection of graphics was labelled as family, either parents or siblings; and a number of these were identified as being very close to the person themselves. Two of the group were married to each other, and placed their partners in

the close category. One person identified friends at Church as close to them, another identified 'the man at the paper shop' in column two. No other people were identified who were outside of family or the support services for people with learning disabilities. Apart from some personal friends, all other people on the sheet were staff (day and support staff), advocates, or connected with Right Track. Three members of the group talked about the importance of parents but explained they had died; the three had siblings - in two instances these lived in the same area, for the other person her sister lived some distance away. The influence of parents and family was important to them.

> People who are not around can still be important [was one of the first comments made by a group member]. 'I think it is important to have family (and friends) around, because they are around for you'. Sometimes people are no longer around, but are important, [was another comment].

The researcher went on to ask the group how they thought people with learning disabilities were seen by the wider community. An initial answer was 'that depends, sometimes they see a positive side; sometimes a negative side'. The group felt perception was heavily influenced by how well known they were to the person making the judgement: 'Yes, they think negatively about you – they don't know you'. In response to a further question, this group member felt that 'negative' meant people were patronising to him. Another group member presented a different perspective, and described a situation in which a person with a learning disability could be misunderstood if their disability was not acknowledged:

> Well, if you have got friends that know you, but if someone doesn't know you have a learning disability - they can't see the signs, if no one ever … you meet that person for the first time they will probably think you are a normal person; they won't think you have a learning disability.

The researcher then explained to people that when the research was written up it would not always be possible to talk about individuals – a label would have to be used, and the researcher would use whichever 'label'[46] participants chose. The immediate reply by one person was 'learning *disability'* and, with the help of the advocates, it was confirmed that other people agreed with this statement. Asked why this term was preferred, the answer was: 'because people will know it's not something you can get over; difficulty can mean you can get over it'.

Later, a discussion started about people making more choices for themselves, and doing the majority of things for themselves: 04 said: '...if it's difficult then you get….obviously somebody else', but with the supporter asking 'how would you like me to help you?' He then went on to give another example from his life about personal decisions: 'I don't always clean my flat but I know somebody who does. I pay them to come and clean my flat for me. I don't like doing it, so I like it' [when somebody does my cleaning for me]'.

The Focus Group were then asked about their views on how they were perceived by the wider community. One person said: 'Well, I have always been included – I have always gone out and done things', but when the researcher asked if that were any easier now the response was:

> No, not really. I think that has been the hardest part of it – hasn't it? – getting people to accept you. They don't understand what we are about – and they are frightened of us.

The first question to the Care Managers (Focus Group Two) sought to explore, firstly, team members' professional perception of people with learning disabilities and, secondly, their view of the perception held by the wider community. 010 was the first to

[46] The debate between learning *disability* and learning *difficulty* (Race 2006, p.4), was explained to participants by the researcher.

respond, addressing the issue of the wider community's perception of people with learning disabilities:

> For the wider community I think they are still the unknown and they get confused with people with mental health [issues]. People with learning disabilities are just like me. They just find some things difficult to do.

Three members of the team nodded as a response to this statement, and then 08 explained why he thought professional and public perceptions were divergent:

> I think one of the ways in which we are fortunate is we get to know people whose lives are between two extremes. Some have lives which are less fulfilled, less happy; we also see people who live very happy lives, not sad, unhappy lives as the general public often see it….

The researcher later commented that people with learning disabilities had identified family and support workers as important relationships in their lives. Care Managers responded to this comment:

03 said: 'It's where people go, the groups they belong to; staff in the day centres and carers as well'. 04 said: 'Friendship groups and families are important to service users', and 03 talked about being part of friendship circles in the day centre when she worked there previously: 'But I think it was part of the work I was doing, more than friendship'.

06 then said:

> … my role [as a Care Manager in a review] is extremely insignificant, I don't have any sort of contextual relationship with the service user…I can read the files and look back; I don't really have any grasp or understanding when I actually meet them at the review of very basic things, such as their needs, or communication skills. Years ago, social workers, you would have had some

> sort of relationship… don't mean to be disrespectful to the Local Authority…it's [now] about ticking boxes and doing the review, and it's not really about meeting the needs of the individual.

010 said:

> I think it is about expectations, and I think families can be quite difficult to work with, because they see their adult child as still a child and needing protection.

Team members' accounts of working with families were mixed; there was awareness of the pressures families could face from changing social care approaches: 08 said:

> I think Social Services has a very short term memory….they [parents] have been working with their sons or daughters for 30, 40, 50 years, and they have gone through all these changes, and each five or ten years new social workers come along and say: no, no, now we have a new approach.

The difficulties team members face when 'coming cold' to an important review was a recurring theme throughout the Focus Group. Being reliant on social care workers' attitude and approach was graphically described in response to a question from the researcher about how closely participants worked with social care workers. 08 identified the positive difference when a key worker wants to make sure the voice of the person with learning disabilities is heard:

> …there is a lot of preparation prior to the review; schools and colleges I have found are very good at the preparation side of things…a creative approach – working with the client, slideshows, pictures – I have found some of the best reviews come from the approach beforehand. We can go in and there is no

preparation prior to the review and we find it difficult to communicate… really get a confident view…that's the problem. About what makes them happy and what makes them sad. It [good preparation prior to the review] can be invaluable really.

4.3 Experiences of 'community care' services

For all the participants in Focus Group One, families were important parts of their lives; whilst living at home, for five of them (01, 03, 04 & 05[47], 06), attendance at a day centre had been an important part of their lives; the other person (02) had been to college and then onto work experience. The timeline[48], as a method, had three purposes: firstly, it illustrates people's personal history against the key periods used to discuss the history of social policy for people with learning disabilities; secondly, what appears in the graphic is a direct translation, constructed under participants' direction, of the way people with learning disabilities talked about themselves – it is their voice and experience and they 'approved' what was drawn. Consequently, this method minimised the researcher's impact which can be so influential (not necessarily intentional) in the direction and content of complex dialogue. Finally, people revealed significant autobiographical details about themselves – both 04 and 05 described how their fear of fits influenced their behaviour when they were younger[49]. Further consideration could be given in the future to accessing the skills required to produce graphics that are reflective of what people say, and recording this in a way they can approve and recognise.

[47] O4 & 05 now longer attends a day centre. They are very involved in Right Track's work and following a national football team is their main hobby.
[48] Figs 2,3 & 4.
[49] The researcher did not put all that detail into the graphic, at the participants request – it was confidential and the research is likely to be read by a number of people.

04 said:

> '1967 I started at the day centre…. 1967 until the 1980s I did the laundry – it was the best part of life really. I had a purpose… before that I just spent all day in bed.

02 told us: 'My Mum died in 1989, I was living with her until she died in 1989.' She then went to describe the decisions she had to make following her mother's death. She was continuing with college and work experience, but also made a decision to live independently, feeling that was her only choice now that both her parents were dead. When asked how this had felt she said:

> two things: a bit upsetting and a bit frustrating because you didn't know what was coming…..I lived with my sister for a little while, but I didn't like it; I thought 'no…you know….I want to live independently….it was my choice'. I said to myself 'I can't live in a big house…to live in a flat is more easy', you know you have got your independence there.

See Graphics over page

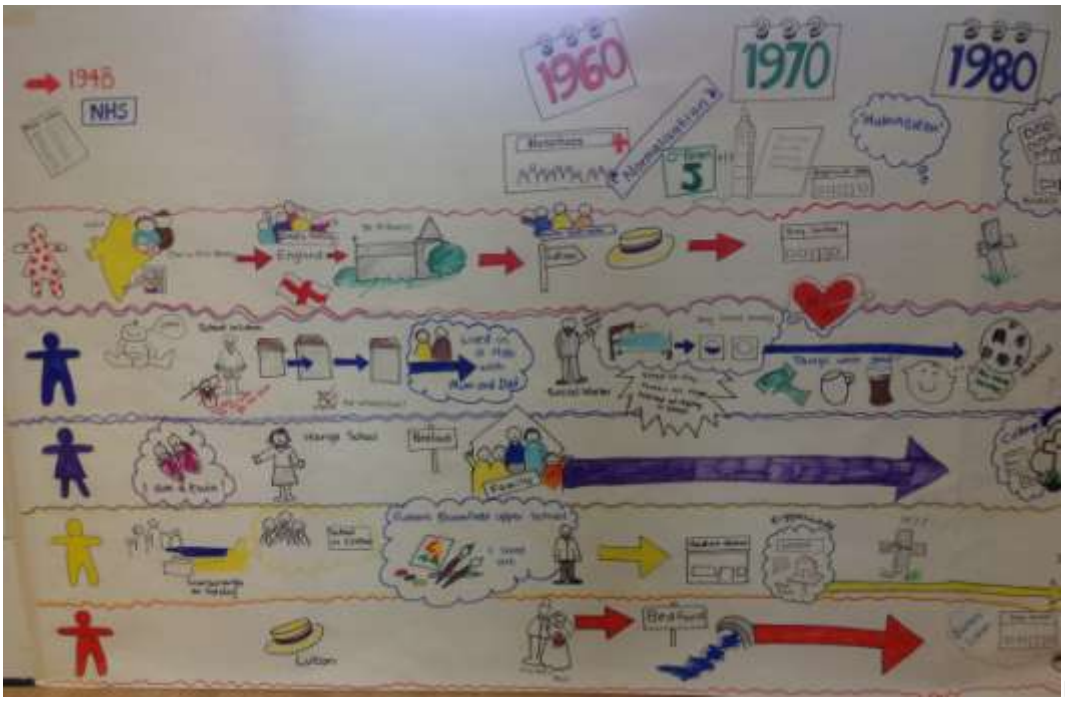

Fig B: A timeline of Community Care history: 1945-1980

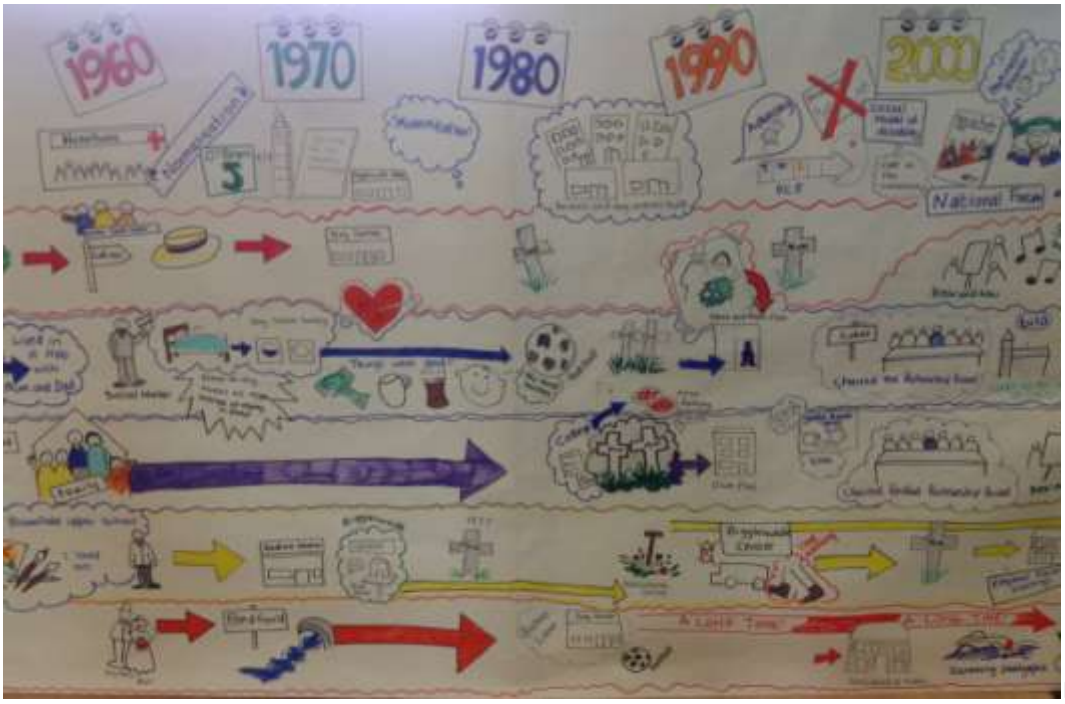

Fig C: A timeline of Community Care History 1980-2000

Graphics continue over the page

Fig D: A timeline Community Care History 2000-10

02 felt that these were decisions that she made about her life. This prompted 04 to make a succinct comment which highlighted how lives can so suddenly be changed by the impact of emotional and practical loss of important people. He said: 'Mum died in 1988. Dad died in 1988. Died within a few months between each other'.

06 was very quiet throughout the Focus Group. With the help of his advocate he explained that he was in residential care and attended a local day centre but, although his advocate tried, Focus Groups were clearly not the best environment to explore his views. However, he was able to tell us how important walking was to him, and how much he loved swimming and football. Another participant, 01, we knew, had lost both his parents, and, as he told us in later sessions, he continues to attend a day centre, but has lived in the community for some years; firstly with another person with learning disabilities, then by himself, and a recent move, agreed with his Housing Association,

has met his desire to live near the centre of the town where he has lived for some years. Both 03 and 05 originate from outside Bedfordshire, and had been in day centres in Cambridgeshire and Hertfordshire; their moves to day services in Bedfordshire were as a result of family decisions. 03 said: 'I used to live in East Hatley….then we moved to Biggleswade'. 05 said: 'we used to live in St Albans, Bedford Road in St Albans, and then we moved to Luton because me dad wanted to move to Luton.' For this person, moving to Luton (to another day centre for her), was a decision made by her dad, but it was to lead her to meet someone who was to become her husband. 04 confirmed, when prompted by his advocate, that he and 05 had married in 1990.

Care Managers[50] made very few comments about the 'history' of community services; they were very concerned with the present, and current changes, as the personalisation agenda is being developed by the local authority. The researcher assumed that the lack of references to the past was partly explained by the fact that only two Care Manager in Focus Group Two had been working in the field long term. Other Care Managers' professional experience was post-*Valuing People* (2001). However, 09 did say [28 years experience in social care]:

> Parent's attitudes and expectations have changed …families are more forward thinking that are coming through. They are tending to think more about the future; they are not thinking 'I have to look after this person until I retire, until I die'…

08 said:

> Things have changed, with things like day services…now, even if there are not services, there is an expectation that we will find a solution in the community…you can access the money, you know, and try and look for

[50] In Focus Group Two.

alternatives. I think that's where there is a massive problem, because services in the community *per se* aren't necessarily ready to meet the needs of our clients.

4.4 *Valuing People* and beyond: experiences of exercising choice and control

Valuing People was a topic introduced to Focus Group One by the researcher to explore its impact on how people spent their time. Several people [by nodding] made it clear they were aware of the White Paper. When asked whether people can think about the years 2000-2001, and whether life changed at all in terms of the things they did and where they worked, 04 made a pertinent comment: 'It was later on, by about 2006, 'I think it could have gone a lot further'.

Apart from the suggestion that the impact of *Valuing People* on people's lives took time, people were also saying they thought there could have been more choice, and that choice should also mean that people can decide not to change their lives: ' 04 said: You will feel forced, pressured to do it.' 02 and 04 had been very involved in Partnership Boards from their start, and 04 cited involvements in meetings as the biggest change in his life post-*Valuing People,* but did effectively suggest that, in his personal experience, Partnership Boards existed for the purpose of ratifying decisions already made.

Two members of the Focus Group now have increased experience of making decisions regarding money through their role as Directors of Right Track which currently [April 2012] has available funds of £20K. People with learning disabilities contributed a great deal to this part of the Focus Group; it was not 'abstract', it was about their lives and

experiences and very real to them. It was also an opportunity to talk of *their* successes and achievements in life; a firm platform for moving forward to achieve their aspirations

See graphics over page

Fig E:

Valuing People 2001

See Graphic over page

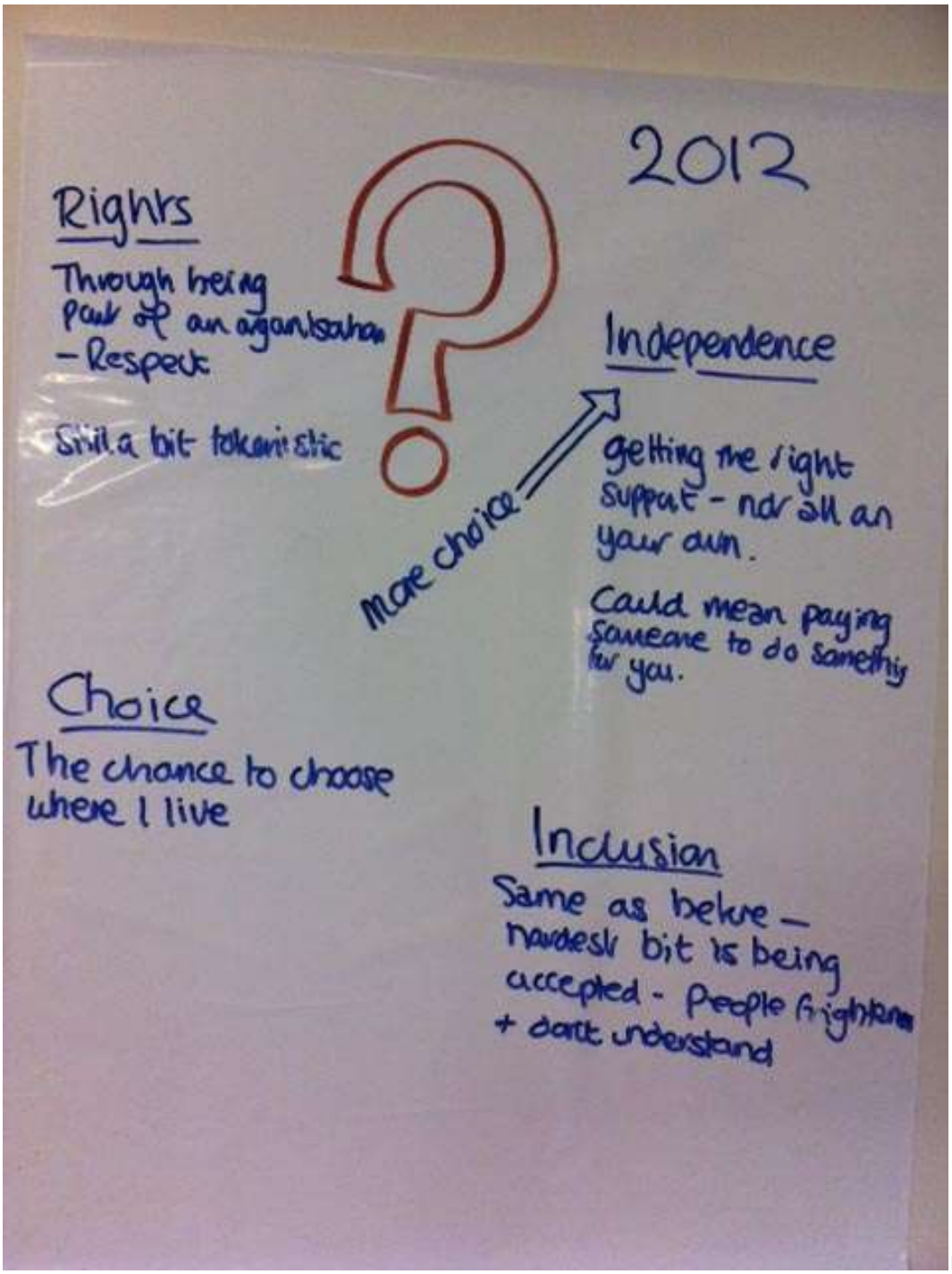

Fig F: Valuing People 2012

In the afternoon session, participants in Focus Group One used Bingo Cards to talk about aspects of choice and lifestyle. Each bingo card represented, as a graphic, an aspect of

'choice' and, as each card was held up, people were encouraged to talk about their experience of this particular aspect of choice in their lives. Below are the key areas that provoked the most discussion in this session.

- *Jobs*

On the subject of jobs, two people had direct experience of work in their lives. 02 told us: 'I used to work at a residential home for people with learning disabilities [as a domestic] part time'. She confirmed that it had been a good experience and when asked who had helped her to get the job, she explained that she had applied for a job as part of a college course.

Two other people said they would like a job. 01 wanted to be a gardener and 03 wanted to do office work. They said they thought they would need help in getting a job, and cited a social worker or a friend as people they would turn to for help and advice.

- *Days and use of time*

People talked about the choices and decisions they made about the routines they lived, and how they chose to use their time with regard to domestic tasks. 04 said 'When I am washing clothes I just do it. I don't have a special day for it.' 02 said 'I decide what time I get up in the morning.' When asked if she always been able to make decisions like this she said: 'No. Not always but since I have been living independently – yes.'

06, we knew, lived in residential home. As referred to earlier, throughout the session he was reluctant to speak, but in a question and answer session with his advocate on this aspect of choice he told us that breakfast time was 7:30 and going to bed was 10pm and this appeared to be a routine of the establishment. He also described his 5 day a week routine at the day centre, but could not tell us how he had decided to come to this Focus Group which was being held on a day he would usually be at his day centre.

However, this person did like going out and walking around Bedford and seemed to be able to do this relatively freely.

❖ *Domestic tasks*

Others talked about the use of their time: 'I clean my flat', said 01. 'I had to learn it, but I did alright once I had learnt it. Thank you very much[51].' 05, whose husband had already told us that they employ a cleaner because they don't like cleaning, said: 'We don't cook on a Sunday. We go out [to a pub in town]. Asked why they made that decision, 04 said: 'Because it's cheaper, and you don't have to wash up do you'?

❖ *Who we live with*

In speaking about friends and relationships in Focus Group One, 04 and 05 were identified as married[52]. When discussing situations where people might not chose who they live with, 02 talked about living on her own and being independent, and said of her situation: 'I mean I lost both my parents – I had no choice – but now I live on my own, but I like living on my own.'

04 explained how he liked living in Luton and he likes the area he now lives in: 'I like it where I am. Yes, I like it right in the town centre – great'. 01 explained how he had moved into a group home, with another person with learning disabilities, but there had been trouble with the neighbours and his friend has moved somewhere else.

❖ *Friends*

[51] 01 had explained that his mother (now deceased) had taught him how to clean.
[52] 04 and 05 had met at a day centre they both attended.

In talking both about 'friends' and sources of help and support when making decisions, people seemed very reliant on formal, rather than informal, sources of support. A lot of contact with people came through professional sources. 04 said: 'People in meetings. I have got friends from the Council – friends from there. I had a meeting and I met them, like Mary[53].'

Talking about his current flat, 01 said: 'Yes, Jane[54] was helping me move and I think she will do it again if I don't like the flat.'

- *Money*

04 brought home the issue that many people face in respect of money: 'Never got enough' but then went on to describe how he used direct debits to manage his finances and would ring the bank if he had any problems. 02 said: '…well, if you want to buy something and you are in a home, you have to ask the staff how much it is, and they take the money out of ….' This person identified electricity and gas as important items to buy. When asked how you decide which gas and electricity to use the response from 04 was 'cheapest'. There was agreement that finding out who was the cheapest and 04 said: 'I am with EDT', 03 said: 'I am with British Gas.'

- *Decision making and control*

[53] A Council employee (not her real name) who attends Partnership Boards.
[54] Jane (not her real name) is an employee of the Housing Association from which 01 rents his current flat.

The discussion about choices around money appeared limited until one of the advocates asked people about the choices they make in their work with Right Track. This created discussion about respect, the relationship between one of being giving information, then making decisions. The researcher picked up on the theme by asking a question: 'Do you make more decisions now in Right Track than you used to?' 'Yes', said 04, who is a Director of Right Track. The researcher asked how it happens? 04 replied: 'Well, you give us information, and tell us what is happening and on that information we decide what to do.' 'Yes, we are now in more control, instead of being under ***** ***[55], we are on our own' said 04. The researcher referred to the fact that a Community Interest Company (CIC) has to follow company rules, questioning whether there was a CIC structure specifically for people with learning disabilities? 04 said: 'There isn't, so we are becoming normal!' 'It comes back to be treated with respect – I think that [referring to the 'status' of Right Track and the Director role] is one of the reasons people see us as normal.'

Being treated with respect was mentioned several times; it seemed important to people.

- *Support, well-being and risk*

Finally, in Focus Group One, the question of people's (professionals, families and academics) concerns about the safety and well-being of people with learning disabilities was raised in terms of the view that living out in the community placed them more at risk in respect of their health and general well-being. The responses suggested that people were pragmatic and not unduly worried about these issues. 04 explained there was a nurse for learning disabilities who helped people when they were in hospital; and then he said: 'eat the right food – they tell you everywhere in the adverts – eat five a day!' On managing your finances and risk of theft 04 responded; 'I have direct debits';

[55] Right Track was initially 'hosted' by an advocacy agency.

and, on safety: ‘you have to be careful, don’t go out at night it can be dangerous for everyone.’ These seemed to be very matter of fact answers. Being given the right information, knowing about the role of the police and so on was seen as what everyone needed. People also identified doctors, family members and support staff as people you might go to if you had a problem. Participants talked about people with learning disabilities receiving support, the right sort of support for their needs. 04 said: ‘if you need support…people with learning disabilities can live in the community, but they need a lot of support.’

See Graphic over page

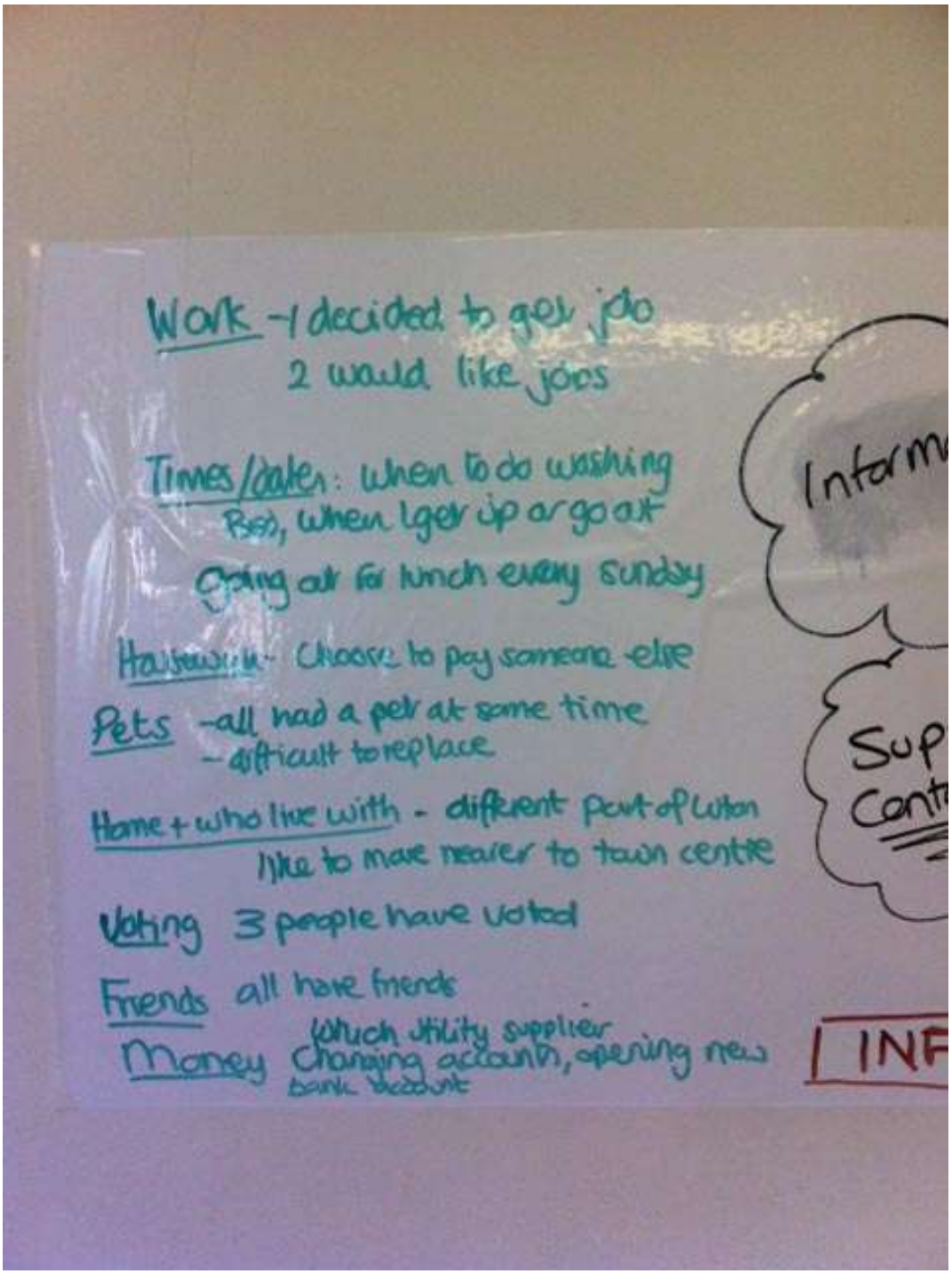

Fig G: Choices 1: What we talked about

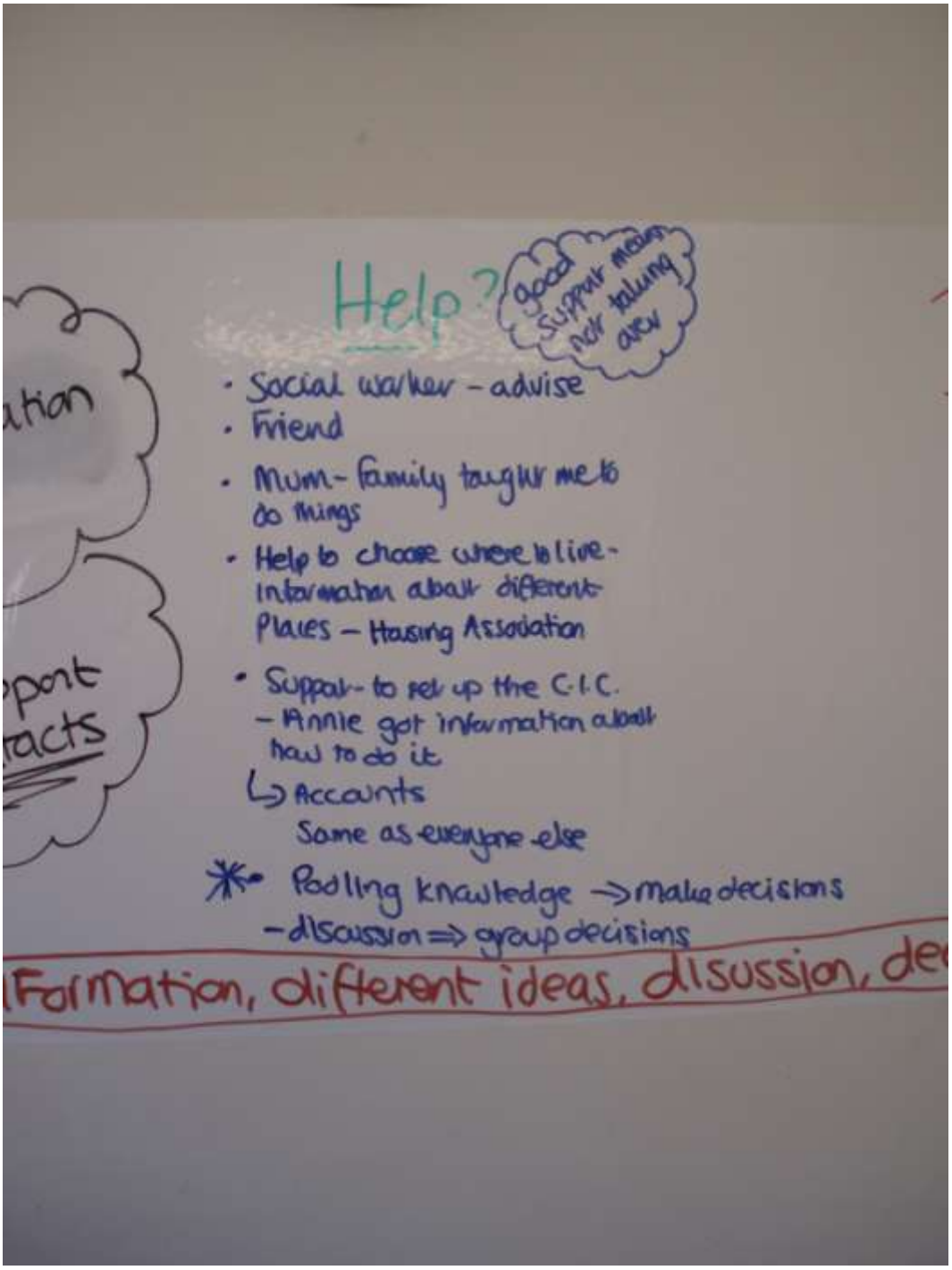

Fig H: Choices 2: Sources of help

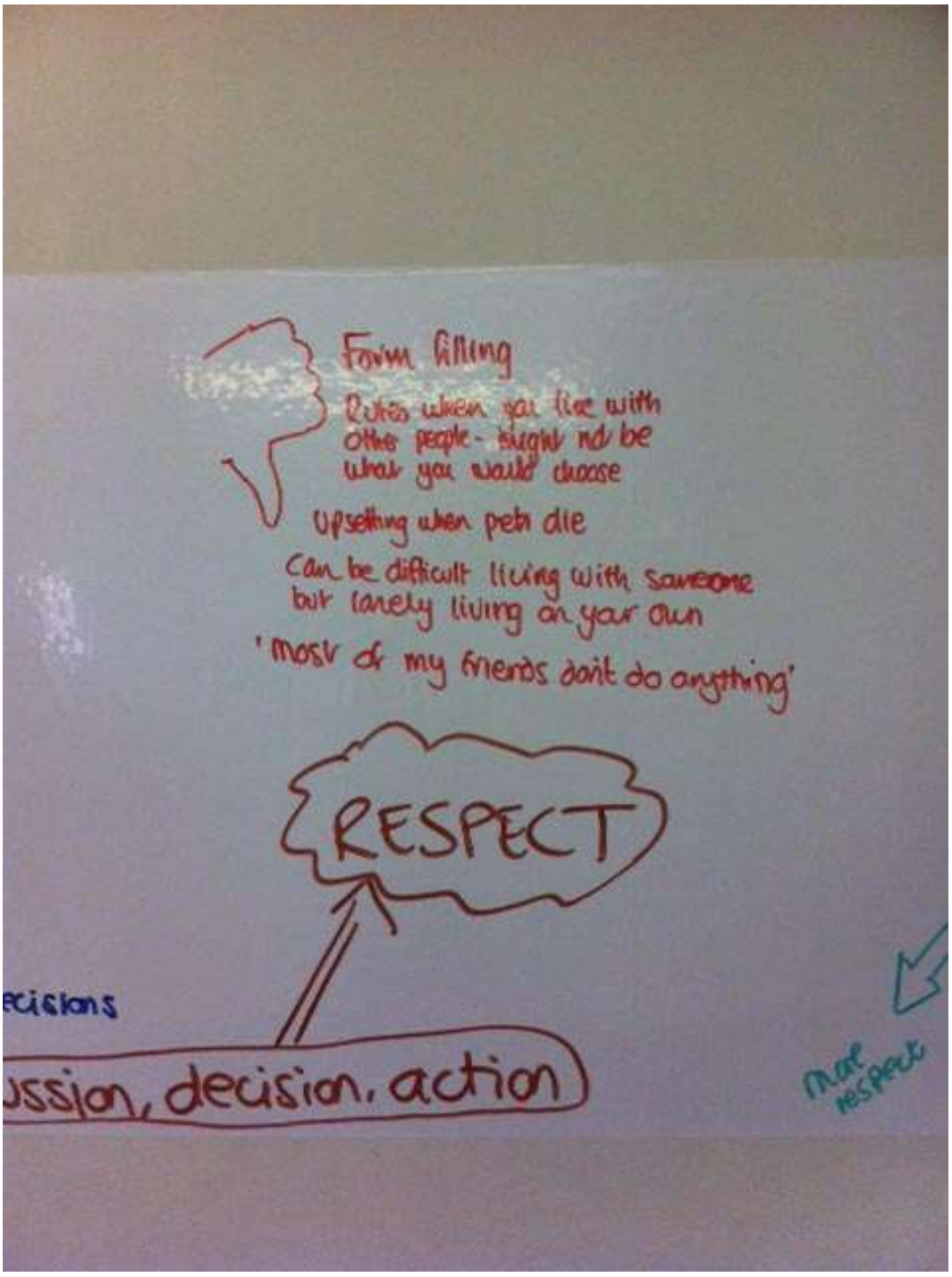

Fig I: Choices 3: What was difficult?

In response a question from the researcher, members of the ALDT[56] linked options for choice and decision making for people with learning disabilities closely to the opportunities and resources available in the wide community. 08 expressed concern about current policies and expectations at a time when government savings are a priority. 04 expressed the view that choice for people supported by social care was limited compared to other people such that they didn't have the same range of choices as everyone else. 09 added: 'It's difficult to feel you are giving choice and sometimes I've had experiences lately where choice is diminishing as fast as I offer it.' She went on to question the basis for the changes currently being made:

> Just because it was the old way doesn't mean it was wrong…if I was a parent of someone with a learning disability there is comfort in knowing it is brick-based and that there is somebody there.

09 then talked about the complications and pressures that can be part and parcel of the choice process[57]:

> Other complications have come into play such as planning permission being granted, buildings not ready when they thought they would be ready, yet homes are closing, so choice is reduced, like 'take this or be homeless'.

07 identified Direct Payments as another burden for carers:

[56] In Focus Group Two.
[57] This referred to how complicated life can be and promises made (about choices or timescales for something to happen) difficult to keep.

> There are a lot of our people, who can't manage a direct payment independently so we always ask the carer, when the reality is that is another pressure, because it is not easy….'
>
> 07 said:
>
> I think for our more able people ….they need help because they cannot manage correspondence and bank statements and then we are asking them to employ somebody as well.'

07 suggested the system and advice available re Direct Payments is beyond her understanding, and certainly is for service users or their carers. She said:

> But the reality of how they have to pay that person is a nightmare…a lot of people do go the agency route, if someone is off sick there is someone else there, and there is that link up if they have a manager, they are overseen.

In Focus Group Two, professionals saw other people's concerns about risk as a major barrier to people with learning disabilities exercising choice and independence. 02 said: 'Everybody has the right to take risk providing they understand the potential consequences of those risks.' 07 had said earlier when talking about choice:

> I think people that support people with a learning disability aren't comfortable with taking so many risks…people [with learning disabilities] want to make choices, but people aren't always too keen to take the risk that choice involves.

06 identified the family perspective on risk as being the biggest problem to the professional who wants to support an individual with learning disabilities with choices or aspiration that might involve risk, but saw this as a much broader issue than learning disabilities:

> From my [previous] experience of child care…parents do have a big hold on the person…they are the people with the voice, and this person is going to get talked down because of the relationship they have…I find in my world you have got the care providers now…they don't want to say too much either because they don't want to upset the apple cart [contracts for services].'

The purpose of Focus Group Three was to create an opportunity for people with learning disabilities and professionals to interact together in the context of the themes discussed in their separate Focus Groups. Specifically, the researcher constructed a role play in which people with learning disabilities identified a personal aspiration which they hoped could be met by applying for a direct payment[58], and explored this with a Care Manager. Eligibility for social care services and for a direct payment was 'assumed', and the focus was on exploring the process for assessment for a direct payment, and how people with learning disabilities experienced the support they received with their personal aspirations. The assessment for a direct payment was recorded graphically, rather than using formal care management documentation.

After the role plays we got together as a whole group. Before discussing the role plays, the researcher wanted to explore the links between past, present and future and explain why. A graphic was pinned to the wall was entitled 'Our World', with a symbol in the centre of the sheet representing a person with learning disabilities at their assessment or review.

See Graphic over page

[58] Direct Payments had been part of the early work of Right Track and they were understood. Personal budgets were new (and perhaps more complex), and not yet understood by participants.

Fig J: Our World

To begin with people with learning disabilities identified people they might like at their review; these were family members, friends. 'Social worker' was also identified, and it was agreed [after a question from the researcher] that a social worker played an important in the assessment/review process because they had the authority to apply for any funding, or support services, identified at the meeting. A1 [advocate] mentioned, at this point, her experiences where people on the periphery of service users' lives may not need to be involved in discussions about personal issues. More creative thinking is required about who comes to a review, or maybe just relevant parts of it.

In the context of the graphic 'Our World', the researcher explained that in a few moments the group would move on to talk about the future, that is, what they hoped to do with a direct payment. The researcher posed the question: 'If we go into this new world, what about the old world, will we just leave it behind?' A range of comments were made; the researcher

wanted to summarise participants' understanding of the situation. He clarified 04's statements [as his speech impediment affected clarity of recording]: 'you want to move forward, and maybe the day centre as a building goes, but the support provided and contact with friends should remain, but you do want more control'? 02 and 04 said 'yes' to the researcher's clarification and 05 nodded.

Participants then went on to talk about their experience of the role play in which they had talked to a member of the ALDT about their aspirations for a direct payment. 04 and 05, the married couple, wanted a season ticket for Arsenal Football Club; 02 wanted to go on holiday, somewhere hot, with a friend who had severe learning disabilities; and 01 wanted to join a local walking club. The researcher asked about the experience of seeking a direct payment for an Arsenal season ticket in 04/05/011s' role play: 04 said: 'Helpful, helpful. He explained what he was doing, how he was doing it.' The researcher confirmed that the professional's role here was giving information. 04 'Yes, and he listened'.

011[59] said:

> It went very well, 04 was very clear really, and 05. That made life very easy – and they knew the cost and I was quite happy so we set about doing a support plan…

'Yes', 04 interjected. 011 went on:

> Who is actually going to support them to get the season ticket in the first place, 04 identified his brother. O4 said yes: 'He gives me a lot of support', and we also talked about how they are in crowds – do they need support and

[59] Care Manager.

that…we looked at a contingency plan…if anything went wrong they would contact 04's brother and he would go and pick them up.' 'Yes' said 04.

011 said: 'I think 04 and 05 are capable people, they can work out problems for themselves…quite a nice little plan to put together really.'

The researcher then asked 04 and 05 if that felt ok? 'Yes' they both replied.

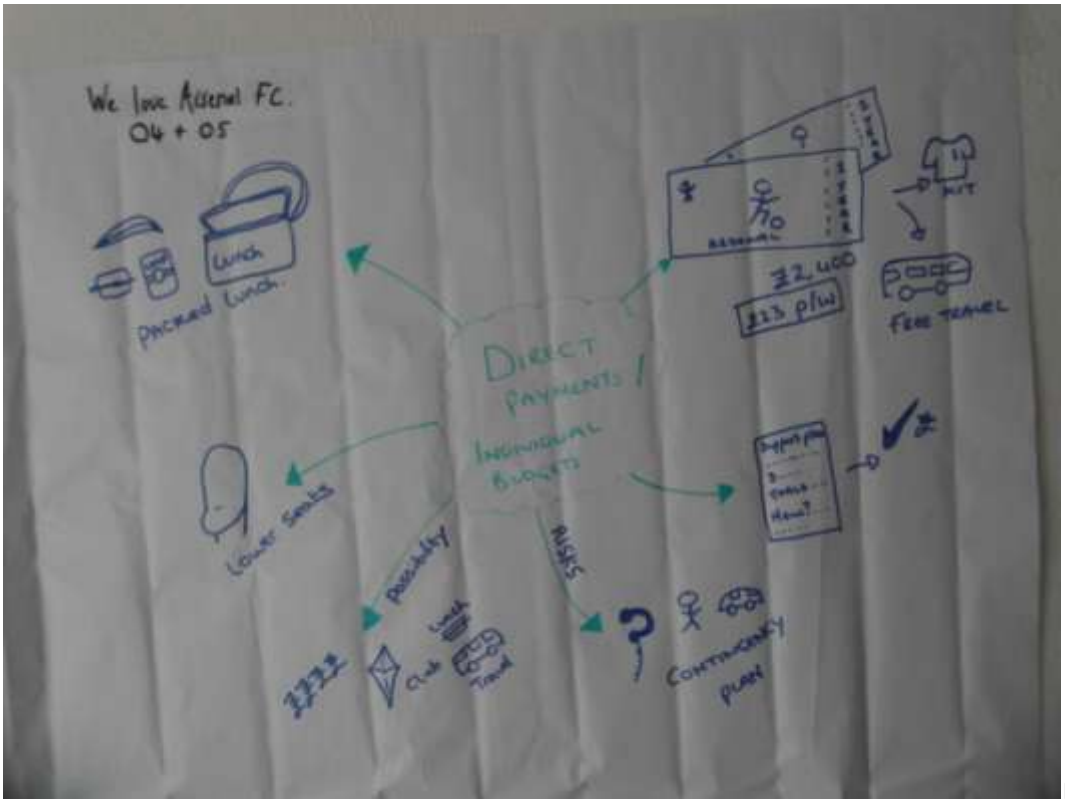

Fig K: Assessment for a Direct Payment: Season Ticket for Arsenal Football Club

The advocate (A1) working with 01 [who wanted to join a walking club], said at this point:

01, one of the things I noticed with 07 with you is 07 knows you, and she knows quite a lot about where you live now and the changes you have experienced…was that helpful?

01 replied:

> I think it was helpful that I had 07, and perhaps if I had someone else it would have made it much more difficult… It went alright with 07 [because she knows me].

The researcher asked the two professionals (07 and 011) if it is helpful to know people when working with on choices and decision making. 07 replied 'definitely'. And 011 said:

> Yes, it is very difficult if you turn up cold[60], especially if the person is not able to advocate for themselves about what they want to do…and it's very dependent upon the family views, rather than the individual views, and sometimes it's a case of they haven't got any ideas themselves, you end up pushing your ideas onto them…and it's a case of where is the choice there?

Talking about people with learning disabilities moving out of 'services' and using community facilities, the researcher asked about Safeguarding. 07 responded:

> I think you talk about minimising risk, but there will always be risk…if the service user is saying 'I really want to do that', all we can do is put the best supports in place, and if something doesn't go the way we planned it then we have done what we can; unfortunately, that is life sometimes.

011 said: 'Yes, it has to be an acceptable risk', and 07 went onto say:

> I think we are a bit more open [to risk], I've recently tried to support someone going on holiday, and it has just been a very slow process…going to

[60] Usually new cases are allocated to the duty social worker who is on duty that week.

> visit airports…looking around St Pancras station…just slow steps to start with rather than just going: 'let's go to the airport then.

The researcher followed this up by asking whether management would challenge this use of professional time. 07 then said:

> I think you are normally in the profession because you care, so there is a reason why you have done something…sometimes when you're there, in that person's home…it's something you can do; it seems a little anal to go 'somebody else can do that and I will send them over next time'.

At this point the researcher was intending to move on, but the advocate [A1] alerted him that one of the people with learning disabilities (04) was trying to say something. The advocate asked 04 if she could feed back what he had just said to her for the benefit of the digital recorder. 04 was talking about some work he had done as Right Track member in a local day centre with a person with special needs who was preparing for a review. 04 said: 'we had a meeting, we did a drawing.' A1 [advocate] explained that the father of the young man was present, and they were trying to find out what the young man saw as important for his future. Showing him videos and playing games they discovered he loved slap stick comedy; and he also preferred working with young female staff rather than older staff. His preference for people was evidenced by video clips of him interacting with a range of people. The father intended to take the videos and drawings to the review meeting which was taking place in the near future. 'He was very relieved…very encouraged' was the comment of 04; and the advocate explained that the father could understand the drawings, and he had photographs and videos as evidence of what was important to his son. The researcher asked what would have happened if the outcome of the session had been a written report. 'It would not have the same impact' was 04's response.

We then looked at the experience of the person who had wanted a direct payment in order to join a local walking club. His advocate (A1) spoke for him, but she was looking at him all the time she was speaking, checking that she was saying what he wanted to put across.

> What you were saying you wanted to do wasn't very complicated [joining a walking club] but it was very refreshing when the professional's response was: 'yes, we can do that.'

011 suggested the key at the moment seemed to be the interpretation of personal support:

> If someone required 10 hours of support [for shopping] but then decided that achieve his/her outcomes (s)he doesn't need one to one support, if (s)he was to buy a computer and do his/her shopping on the internet they would actually get the equipment…by a different interpretation of a personal budget…whereas the walking equipment may not be…because there was no initial assessment for one to one.

At this point a coffee and comfort break was agreed, and that when we reconvened we would talk about support plans. When the second session recommenced A1 [advocate] told us about what 01 had said about support (joining a walking group):

See Graphic over page

Fig L: Assessment for a Direct Payment: Joining a Walking Club

You said first of all you wanted the staff, or the social worker, somebody, to get you the information about walking groups'? 'That's right', 01 said: A1 went on: 'so that was the first thing; that was information'?

(01 said 'yes').

So you wanted them to make the initial contact and then you wanted the staff to go with you for the first time. But that needed to be a member of staff who enjoyed walking… that was very important wasn't it?

'That's right' was 01's response. The advocate went on clarifying:

'and the group to contact you if it was cancelled so you didn't turn up and find nobody there…you thought it would be useful if staff had a list of dates…so that was the information you wanted in your Support Plan'.

01 replied 'yes please' and the advocate said to 07 [one of the professionals]: 'How would you present that to a panel – I don't know'?

07 replied: 'Well, we have a special document we have to use…so normally what I do when I go out to see people is that I just translate into the way it needs to be for panel…'.

The researcher asked the professional about her role as an ally of the person with learning disabilities; 'in a way, [you] sit between 01's explanation, his form of explanation of what he wants, and the plan that needs to go round the system'.
'Yes' she replied.

The researcher then said: [to clarify the point that was being made]

> …in terms of your ally role, there are the informal bits; i.e. you happen to know the managers (of the services that support 01), the people that support him. If you didn't know them, you would be in a slightly different position presumably?

07 replied: 'Yes, it would take a bit longer to go out and find who I needed to contact'

The researcher then asked: 'I just wonder whether, sometimes, a person requesting an activity that none of the professionals in the team are actually interested in – what are the chances of everybody saying, 'we can't do that''? 07 replied:

> I had one the other day that I wasn't the slightest bit interested in…I didn't even know what it was…so we went upstairs and sat together at his computer for 30-45 minutes; we looked where they were, how much a ticket was, just as you do…I don't know what we would do without the Internet.

A1 [advocate] said at this point: '…often support is helping people to do the research with them?' 011 said:

> I often think our role is as an 'arranger' and a 'fixer' and that is where brokerage could step in and take on that role – we are a bit behind the times on that…but I think social work time doesn't necessarily allow the research into activities that we would like.

The discussion returned to the forms of recording people's wishes or aspirations and the advocate (A1) said:

> The important thing is then for 01 to have something that makes sense to him, for him to check what is happening…and if you only have the 'official' support plan, which perhaps uses words that don't make sense, it is more difficult for you to say 'it is not happening because of this …'

We then moved on to talk about the third role play, where the person with learning disabilities (02) wanted to use a direct payment to go on a holiday abroad with a friend who has a severe learning disability. 02 then talked about her experience of exploring options for a holiday with her friend. She and the ALDT team member (07) had explored the choice of holiday location, and then information about the 'technical' detail in arranging a holiday. In response to a question from the researcher, 02 confirmed that the professional had not tried to dissuade her from her choices because it was too complicated [staying in England rather than going abroad], or risky [catching a disease].

See Graphic over page

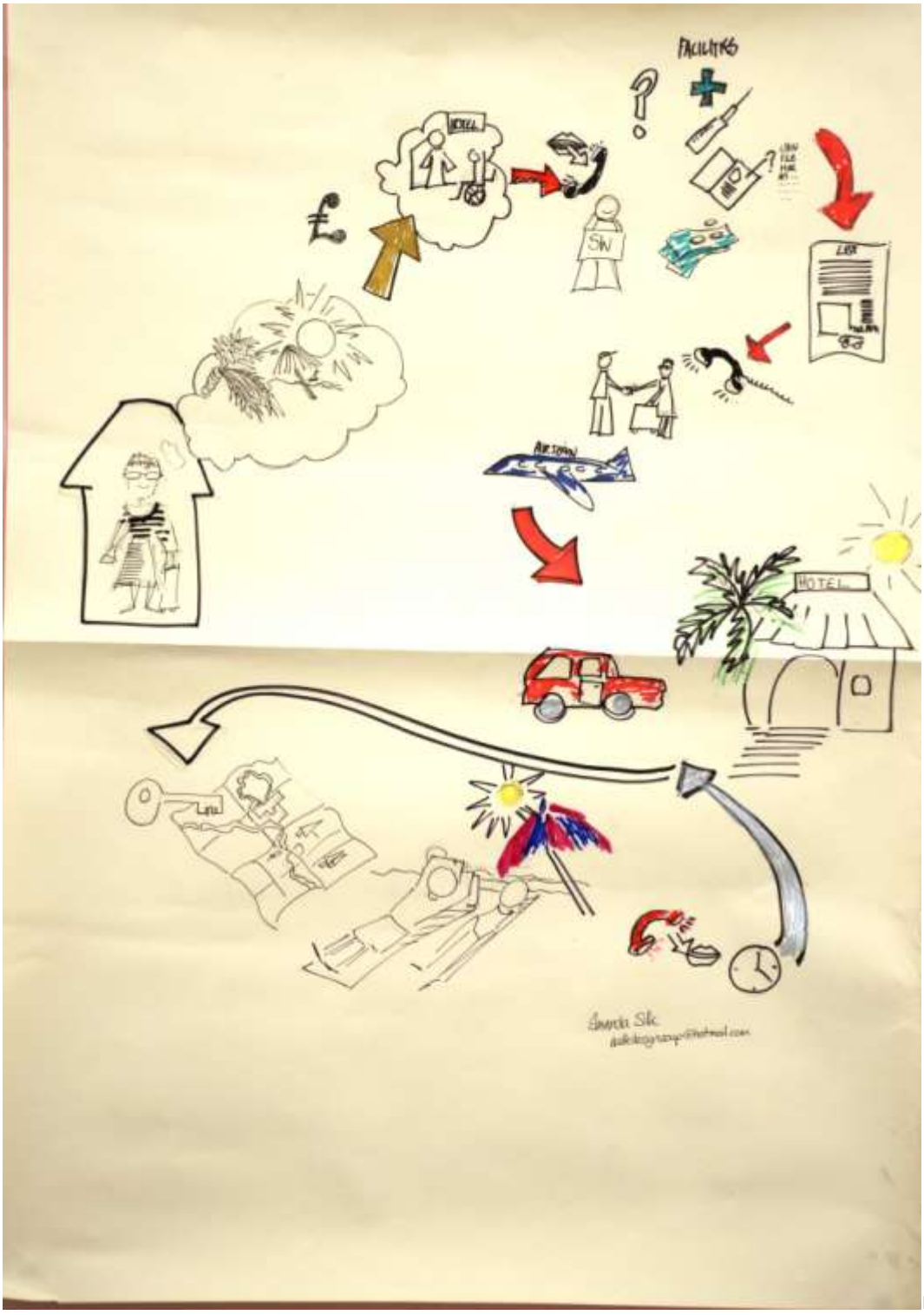

Fig M:

Assessment for a Direct Payment: Planning a holiday

02 talked about working with the professional on things like wheelchair access and checking that passports are up to date. The researcher commented that passports are something everyone going on holiday abroad has to deal with, but managing a wheelchair is special and more complicated. 'Yes', said 02[61], and told us that in the role play they had talked about injections against things like malaria. Attending to these factors are important for people's health and their overall safety. 07[62] said: 'Yes, because we sort of went through it step by step, didn't we?'. 'Yes' was the reply. 07 said: 'And we literally went through it step by step literally…broke it right down…and you were telling me how independent you were, weren't you?' 'Yes' replied 02: 'So, 07 was then saying, on each step we were saying, do you need support there? Do you know what support you would ask for? Is there something you need me to get you for support?' 02 was keen to stress her independence: 'I am independent but I am taking a friend with me who has got (severe) learning disabilities and risks – but I have got more independence so I can help her…'. There was some discussion about what was meant by 'independence'. The researcher said: 'You like people sometimes to help you with your diary?' 'Yes', 02 replied, and the researcher followed this up: 'and then you feel more comfortable…yes?' 02 replied 'Yes' and the researcher fed back to 02: '

> So, although we are talking about people being independent, and you are independent, like all of us, there are little things you need…so for somebody to be your ally, they will need to respect the fact you are independent but they know…and we are all like it, there are bits – we need that support?.

'Yes' was 02's response.

At this point we were at the end of quite a long day, and the session was concluded.

[61] Participants with learning disabilities.
[62] Care Manager.

Summary

People with learning disabilities expressed the wish to be respected and also acknowledged the importance of supportive relationships if they are to achieve their aspirations, and for their voices to be heard as they define the ways they would like to experience that respect and support. Care Managers expressed respect for people with learning disabilities (and their aspirations) but also of difficulties they faced in their key role in assessment and review. The next chapter explores these issues further.

5. Analysis

5.1 Introduction

The literature review highlighted the impact of social policy – through the interventions and roles of professionals - on the lives of people with learning disabilities and their families, from the 1913 Mental Deficiency Act to the present. A significant shift in perceptions of 'learning disability' took place over that time period, particularly in the last fifteen years, as direct payments have offered people alternatives to segregated services and *Valuing People* (2001) introduced the principles of rights, independence choice and control for people with learning disabilities. Such opportunities and principles, however, may not be a reality in the daily lives of many people with learning disabilities (Walmsley 2006, p.2; *Valuing People Now* 2009). The fieldwork explored the themes identified in the literature review from the perspective of one group of people with learning disabilities.

The Focus Groups explored relationships for people with learning disabilities against a background of their personal experiences of community care services. In Focus Group One people with learning disabilities gave accounts of relationships, their experiences of community care 'services' and the impact of *Valuing People*. The responses to parallel questions to Care Managers in Focus Group Two identified their perception of people with learning disabilities, together with participants' understanding and experiences of their role in supporting them. Role-plays were used in Focus Group Three as a means of modelling relationships where Care Managers acted as 'allies' to people with learning disabilities and their aspirations for the future, including the opportunities and benefits offered by direct payments or personal budgets. Synthesizing this information draws out a model of relationships that people with learning disabilities believe values them as individuals and supports their aspirations. The starting point for this was to read (and re-

read) Focus Group transcripts to identify and understand patterns underlying discussion (Richards 2009, p.95; Saldana 2009, p.5). A simple process (pen and coloured markers) was used to mark these up in the margins, and then collate them.

Firstly, people with learning disabilities in this research identified family members, staff from services and people in the network related to Right Track's work as their 'important' relationships, referring both to staff and people in their network as 'friends'. Care Managers were not mentioned as part of people's important relationships, but in Focus Group Two Care Managers expressed respect for people with learning disabilities, and this was reflected in the role-plays involving people with learning disabilities and Care Managers in Focus Group Three. When participants talked about their life experiences the influence of parents was very apparent, and the potential impact of this powerful influence on the role of Care Managers at the point of assessment, or review, will be described later.

Secondly, later in Focus Group One, people with learning disabilities identified three important attributes they wished to see in their relationships with professionals which would form a firm foundation for achieving people with learning disabilities' aspirations for the future. These were: (1) being treated with respect as an individual; (2) receiving good and reliable information about changes and new opportunities; and (3) retaining ultimate control over any decisions made about their future life options. These will be explored further in this chapter.

For participants with learning disabilities, it was family and friends, and then the professionals connected with services, who formed the significant relationships (and potential source of support) and who were central to people's lives and their aspirations for the future. They valued these past relationships and services; they talked about parts of their past – relationships and services – with respect and nostalgia, wanting those

experiences to be recorded alongside the relationship chart to emerge from that activity.

5.2 Families and 'Better Services'

For participants in Focus Group One, their experiences of transition into adulthood, and their families, was within the framework of the social care policy laid out in the 1971 White Paper '*Better Services for the Mentally Handicapped*. As the title implies, the thrust of this policy was to provide services for the increasing numbers of people with learning disabilities who were by then living at home and who would have attended Special Schools provided by the Local Education Authority rather than being cared for in National Health Service special hospitals. The concept of the 1971 White Paper was 'care' (Walmsley 2006, p.93), with the aim of supporting families in that important role; it was an acknowledgement of parents' critical function as primary carers, the beginnings of a change from parents being told by the medical profession 'put him away, and have another child'[63] (Rolph *et al* 2005, p.49).

The significance of people's history: linking past, present and future

It is perhaps not surprising that parents were a significant relationship, but important to note that this is a generation who were brought up to value services; the fruits of the hard campaigning by post war parents were seen in the buildings housing specialist services that appeared in the towns around the county as the 1971 White Paper was implemented. Service models were firmly established, and significant financial investment was committed to sustain them. The alternatives, offered in the twenty-first century, are less visible, and principles like inclusion could be seen as intangible and risky, so either ignored or resisted.

[63] When learning disabilities was diagnosed in a child.

The influence of deceased parents was noticeable in the relationship map activity in Focus Group One. This factor may have been related to the particular composition of the participants; three of the group were older, and they all drew attention to the influence of deceased parents. These, obviously, would not confront or support Care Managers as a physical presence now, but their influence may be an explanation for participants' attitudes, positive or negative, towards changing ideas. The life experiences of 01, 02 and 04 drew particular attention to continuing parental influence. 01 and 04 talked about the influence of their mothers on their lifestyles. Both 02 and 04, talked succinctly in the Focus Group about being thrust into new choices and decision making whilst dealing with the emotional experience of losing parents – the very people who, up to the point of their death, had taken the lead in any decisions that needed to be made for the family, specifically members with learning disabilities. Past experiences of services which 04, particularly, articulated as being a positive influence on his life, also involved important relationships and influences. They are early life influences which remain part of people, and need to be taken into account when discussing people's futures.

As part of the argument for new service models, the limitations of past models are identified by planners; in policy presentations, the nineteenth century hospital model is associated with lack of rights and personal autonomy, and post-war community care models with a continued failure to tackle segregation (Ryan and Thomas 1987, p.47; Race 2002, p. 31; Stevens 2004, p.236; Williams 2006, p.54). Nonetheless, in the story of an individual's life – as 04 expressed in the Focus Group – being part of these services brought out accounts of services that provided, firstly, a purpose for the individual; secondly, important friendships with other people with learning disabilities; and, finally, positive memories of staff whose approach could be challenged by present day values, but who were an important part of a person's life experience, or personal history. A key message from this research is that Care Managers undertaking assessments against present day policies and process may miss the significance and impact of past

relationships, values and beliefs on peoples' lives. Assessments should be sensitive to, and record, the intangible aspects of their lives, the influences of people perhaps no longer around, feelings, history and networks. A building, such as a day centre, may disappear – and may need to in order to fund new strategies – associated memories and friendship should, however, be recorded and retained. Linking, rather than separating past, present and future, assists people to develop, and build their own identity.

A growing body of work (see, for example, Atkinson *et al* 2003) draws attention to the importance of people with learning disabilities being able to explore, evaluate and present their history, as part of reminding us of what it might be like to experience changing interventions as political imperatives have created new social policy initiatives. The point was made recently, and succinctly, by Jan Walmsley in a keynote address to the Scottish Consortium (2011) when she proposed that learning disability policy has: 'lurched from one gold plated solution to the next, each repudiating the past as unenlightened or just plain wrong'.

The point is not that people with learning disabilities cannot embrace new ideas but, like many people, they are more comfortable moving forward if the past is recognised, rather than ignored, or even denigrated; links between past, present and future, should be sustained. People with learning disabilities need support to record their history from the organisations that pre-empt the changes, which have a responsibility to ensure that ideas, professionals and advocates are geared up to enable this. Social policy can be about significant changes of direction, which also have a tendency to be insensitive to personal experience and history; policy may be an aspect of the past but, for people with learning disabilities, the past is about their lives and personal experiences.

5.3 Daily lives and the impact of *Valuing People*

In the second session of Focus Group One, people talked about their experiences of life in the community: where they lived; their lifestyles; and choices and decisions they

made[64]. Employment options have been a major discussion point in both *Valuing People* and *Valuing People Now,* and access to work opportunities has been seen as a key aspiration for people with learning disabilities. Both 04 (who is now of retirement age) and 02 (who worked as a cleaner in a home for people with severe learning disabilities) have been employed in the past. None of the participants is currently employed, and although two people did mention employment prospects, considering the importance it is given in *Valuing People* and *Valuing People Now* it was not a subject that provoked detailed discussion (when the particular bingo card was put on the wall) in the Focus Group.

People did talk a great deal about their daily lives, where they lived, and the sorts of 'decisions' that life entailed. The evidence that emerged was that living 'in the community' exposed people to more responsibility and choice (01, 02, 04 & 05) in relation to the domestic and leisure aspects of daily living. This fits with the picture described in the wider literature, although there is a note of caution that variability has been found. Simply having the service model does not mean people experience the same outcomes (Emerson 2004, p.79; Kozma 2009, p.193). 03 (who lived with family) and 06 (who lived in residential care) provided very limited examples of choice. Two people (04 and 05) were married and living in their own rented accommodation and employed a cleaner. 03 had chosen to live alone, in a rented flat. 01 had lived in a shared group home following the death of his parents, lived with one other person for a while, and was now living alone. 01 suggested there were good points about living with someone else and to living alone; he was very open to the possibility that he might choose to change his living arrangements at some time in the future. These four people were able to identify a range of daily living situations where they exercised choice and a degree of control over their personal lives: decisions about when to go to bed, and when to get up, that were related to what they had to do during the day; doing your washing when you felt like it, as opposed to a certain day; choosing to pay someone to

[64] Bingo cards, shown to the group, represented the subject to be discussed: Jobs; decisions about use of time; pets; choosing where you live, and who with; voting; friends; money.

do your cleaning rather than doing it yourself; and choosing to go out and eat because it was cheaper and avoided the washing up. Budgeting seemed to involve choice (which energy provider to use for example) but could also involve requiring support (04, for example, received help from his brother, but also found direct debits and the bank very helpful). In Focus Group Three 01, 02, 04 & 05 gave further examples of choices in their daily lives. In their Right Track role, 02 and 04 received support to manage their diaries for meeting etc, and they both had 'company' debit cards so they could access money for taxis and travel.

Direct Payments (and Personal Budgets)

None of the people with learning disabilities who participated in Focus Group One had experience of direct payments, but one way in which their expressed wish for more control over their lives could be achieved was through the choices potentially available to recipients of a direct payment and/or a personal budget. The opportunities people hoped could be funded by a direct payment[65] related to relatively low key activities; they were not particularly expensive, and concerned life style choices many other people like to enjoy. Two could be defined as mainstream leisure activities which might increase participants' opportunity to demonstrate the principle of inclusion. One of these was regular attendance at the games played by a national football team that would involve travel from Bedfordshire to London. The second was to become a member of a local walking club and to participate in its activities. The third participant wanted to go on a holiday abroad; this would involve the gathering of information and then undertaking tasks relating to applying for passports, booking accommodation and travel, as well as taking care of health needs by attending to vaccination and so on. The person concerned (03) added to the breadth and 'complexity' of the situation by stating that she wished to take a friend with her; a person with more severe learning disabilities. This necessitated researching travel arrangements and hotel accommodation with a particular emphasis on the access issues for a person using a

[65] In the role plays in Focus Group 3.

wheelchair, suggesting that 03 was expressing her aspiration for a direct payment, but also using the opportunity to draw attention to the particular needs of some with special needs – a group of people she had been working with in her Right Track role.

The evidence from Focus Group Three was that the experience of sharing aspirations with a professional during the assessment process was important in terms of the nature of the relationship, and the way in which information was gathered, and the final decision made about the use of a direct payment. The time given to gathering information was critical if people with learning disabilities were to be enabled to make their own decisions. The three people who went on to participate in Focus Group Three, and role-played applying for a direct payment with a Care Manager, made positive comments about that experience; comments which focussed on the quality of the information and the way in which the Care Manager explained what they were doing, and why, as the assessment progressed. Care Managers talked about a shared process in which they and the person with learning disabilities explored and exchanged information. A positive experience of applying for a direct payment is an important determinant of the quality of opportunity afforded by the outcome for the individual concerned.

Whilst the people in this Focus Group had not experienced a direct payment to date, this may be related to lack of opportunity and connected to the 'older generation' to which they belong. This mirrors a national picture[66] of younger people with learning disabilities, actively supported by family, embracing new kinds of daily living, and activity, which result in people feeling more in control of their lives. Retaining some traditional services was still a chosen option. In Control also reports (Hatton *et al* 2008, p.50) that 82% of people (across all social care groups) in the individual budget pilots changed the services they used, but others continued with traditional services; day centres would continue to be used but people experienced more choice about the timings and level of frequency they attended. The reality is that new policy initiatives

[66] In the individual Budget Pilot studies.

rarely come with development funding; this funding comes from transferring money from existing service provision. Where this is the case it is important to understand the value these services have for people with learning disabilities and replicate them in the new opportunities[67]. Perhaps new and traditional opportunities have to run alongside each if real choice – including continuity and valued relationships – is to be an outcome for all people.

Valuing People

In talking about the impact of *Valuing People* (2001), people with learning disabilities could evidence changes in their lives after its publication, but made a crucial point that changes took time. One participant in Focus Group One expressed the view that it was five years (2006) before the impact was felt on the lives of people with learning disabilities in what was then the old County of Bedfordshire and Luton Borough Council. No doubt local authorities would have recognised the importance of the White Paper but (as the researcher remembers through personal experience), although discussions at senior management level started immediately on organisational change to deliver the principles of *Valuing People*, subsequent policy guidance (LAC(2001)23) had to be absorbed; and it was some time before the impact of *Valuing People* worked its way through management teams to frontline teams. Even then, the researcher suggests, local policy, financial and human resource issues dominated the debate, and the impact on people with learning disabilities remained secondary. For both 02 and 04 particularly, the most notable changes in their lives concerned attendance at meetings as people with learning disabilities began to be 'consulted' about service development. The principal vehicle for developing and overseeing change were Partnership Boards (LAC (2001)23, p.3), and both 02 and 04 have served as Chairpersons of local Partnership Board, as well as being involved in other meetings. Both noted the personal, positive

[67] For example, where traditional day services offer friendships and important networks for individual people with learning disabilities, these intrinsic values could be replicated in some form in the replacement models.

impact of this involvement in their lives, but reflecting back on their experiences they felt that Partnership Boards' main role was ratifying decisions already made elsewhere. This reflects the researcher's professional experience at that time[68], and was further evidenced in the literature search: the complexity of local authority financial and human resource regulations and practice often did not accommodate those principles that support personal choice and de-regulation. Nationally, Glendinning *et al* (2008) found that it was not possible to create one individual budget from a range of complex, funding options – with competing regulations - available to people from different government departments.

5.4 Care Managers as allies

Four aspects of the Care Manager role emerged from the Focus Groups. Firstly, Care Managers have a defined and important role in assessment of people with learning disabilities, which can include an assessment for a direct payment. Secondly, although Care Managers were not included in people with learning disabilities' 'important relationships', in Focus Group Two, Care Managers expressed very positive perceptions of people with learning disabilities. Thirdly, Care Managers did articulate a feeling of insignificance at an assessment or review meeting where family and/or support workers were present; these people knew the person with learning disabilities well, and the Care Managers' own knowledge could be limited. Finally, Care Managers expressed concerns about the support people can access in understanding and administering a direct payment together with concerns about quality of support available; one Care Manager expressed a view that traditional service models, that had served people with learning disabilities well, were disappearing with nothing tangible to replace them.

Care Manager role

[68] The implementation of *Valuing People* from 2001.

Firstly, the central importance of the Care Manager's role in assessment and review is defined in the 1990 National Health Service and Community Care Act (Parker and Bradley 2005) and has been the subject of much debate since then (Lymbery 2001; Scourfield 2004; Ferguson 2008). A number of factors influence what might appear to be a straightforward process of assessment or review. Eligibility criteria and funding are a key part of the debate, drawing attention to the Care Management role in gate keeping and rationing resources. The main focus of this research[69] is the impact of the nature of people with learning disabilities' relationships with others and its impact on their aspirations. In Focus Group Two issues of available resources was mentioned, but Care Managers seemed to be freed to an extent in this discussion from the dilemmas of their gate keeping role (Harris 1998, p.855; Lymbery 2001, p.377), and able to explore social work issues around active listening, counselling, assessing and finding practical ways to help service users (Martin 2010, p.21).

Care Manager Relationships with people with learning disabilities

Secondly, in Focus Group One, people with learning disabilities did not appear to recognise the role Care Managers (the term 'social worker' is more familiar to them) might play in assessment, including the potential to be an ally. The omission of Care Managers as an important relationship may reflect the individual position of the six people in the Focus Group and their current networks, or it may be that assessment or review are relatively infrequent activities compared to the interactions that individuals have with family members, or others more directly involved in their day to day activities. Equally Care Managers, in the eyes of people with learning disabilities, may be associated with meetings which raised expectations, but did not deliver an outcome. Nonetheless, in Focus Group Two, the positive views Care Managers held of people with learning disabilities came across strongly, and in the (third, joint) Focus Group, and the role play, people with learning disabilities commented positively on their interactions

[69] The word limit of 30,000 words demands a particular focus on an issue; the importance of funding and market development in creating new opportunities for people with learning disabilities is, however, acknowledged.

with Care Managers; and 01 specifically attributed this, in part, to his past working relationship with his Care Manager (07). Four key valued attributes for a relationship with a Care Manager were identified as part of their assessment and review role with this group of people with learning disabilities, as follows.

(1) Working jointly with the person with learning disabilities when exploring options, and explaining what you are doing, and why.

(2) Giving people more control over the decisions made about their lives.

(3) Providing good and reliable information to underpin the individual's choices and decision.

(4) Advocating for the individual's needs and rights – in an imaginative way that highlights and reflects their aspirations – acting in a translator and interpreter role that goes beyond recording discussions and meetings in professional language and formats.

The role-plays in Focus Group Three illuminated the nature of the relationship between a person with learning disabilities and a Care Manager where dialogue was forged in joint participation and co-production[70]. Earlier, in Focus Group Two, Care Managers' perception of people with learning disabilities was illustrated by one Care Manager who said:

> …we don't view [form an opinion of] people until we see them. We go out to see what their needs are; we don't have an overall judgement about people with learning disabilities.'

[70] Co-production refers to an active input by people who use services, as well as - or instead of – those who have traditionally provided them. It contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else: SCIE Briefing 31 (March 2009).

The second statement by a Care Manager in which the importance of the individual person is stressed[71] links to National Occupational Standards for Social Work (Topss Partnership 2002; Parrott 2010, p.xi) which formed a key part of social work training for the last ten years. Specifically, value a, requires social workers to:

> Have respect for individuals, family's carers, groups and communities regardless of their age, ethnicity, culture, level of understanding and need.

The professionals in Focus Group Two never made specific reference to the underpinning values of their professional training, but they certainly highlighted the contribution knowledge of the individual can make to the overall perception of any group of people. One Care Manager challenged the perception of learning disability as a problem and, in the researcher's view (judging by facial expressions and body language), was supported by colleagues when he said: '…we also see people who live very happy lives, not sad, unhappy lives, as the general public sees it'.

Bayley (1997, p.20) identifies reliable assistance and guidance as important parts of an empowering relationship. In addition, very important personal aspects of a relationship are attachment and intimacy as well as social integration and opportunities to nurture. Bayley also identifies 'reassurance of worth' as an aspect of a relationship that gives the individual receiver competence in some role. Care Managers who provide assistance and guidance based on a positive assessment of the receiver's role are demonstrating a willingness to be an ally.

Later, in Focus Group Three, a very key ally role emerged for the Care Manager as the next stage of the process[72] was discussed. The Care Manager working with 02 talked about taking her assessment to their manager, or to a funding panel. This part of the process would not directly involve 02 (the person with learning disabilities) – as she

[71] As opposed to a generalised label assigned to a particular group of people.
[72] After the completion of the assessment or review and the initial paperwork has been completed.

would not present at that meeting. In one sense this is perhaps the most critical part of the Care Manager's role as an ally – representing the person's aspirations when that person is not actually present. The key elements of this ally role emerged from the discussions as: advocating for the individual's needs and rights – in an imaginative way that highlights and reflects their aspirations, a translator and interpreter role that goes beyond recording discussions and meetings in professional language and formats.

Feeling insignificant

The third point was in contrast to the positives above, but also important for the professional's relationship with a person with learning disabilities. In Focus Group Two, Care Managers were also clear that they faced problems with their assessment and review roles. Care Managers said they often felt insignificant in the presence of family and support workers. They often felt thrust into an assessment or review situation knowing very little about the person with learning disabilities, in particular that person's aspirations for their future, and had very limited time to assess, or review the situation. Families and support workers, on the other hand, knew the person well. Care Managers struggled to know whether views put to them in a meeting represented the aspirations of the individual or the views and needs of the family or support worker[73]. Care Managers implied concern that both staff and agencies could easily put their own interests (keeping contracts and roles that felt comfortable) above the needs and aspirations of the individual person with learning disabilities. Risk aversion was also referred to as a stance relating to both staff and families.

In keeping with the values and ethics of social work, however, Care Managers expressed respect for the needs of families as well as the needs of the individual person with

[73] Communication methods (verbal and written) used in a meeting can disempower the person with a learning disability.

learning disabilities and an awareness that they might have to manage potentially competing/contradictory interests. Care Managers were able to articulate an understanding of the important, demanding role families have in caring for a family member with learning disabilities; and empathised with families who were also susceptible to changing professional advice and models of support services brought about by shifting models of social care provision. They were also able to recognise the different experiences and expectations of families rather than seeing them as a singular group.

Although recognising the danger of generalisation, older families were seen by professionals as potentially reluctant to lose familiar buildings-based services in favour of individual-based models that were seen as involving unacceptable risk. Care Managers understood the extent of this anxiety, and one explained that a person with learning disabilities could be seen as a 'child' in the eyes of the family and not expected to have a legitimate view on things they 'did not understand'; in these situations, families were perceived as not comprehending why a Care Manager might want to explore such issues with the person with learning disabilities him/herself. Although professionals play a key role in both assessment and reviews for people with learning disabilities, other relationships come into play which often impinges upon the dynamics of the meeting, influencing perceptions of the person with learning disabilities, their needs and aspirations. Relationships can be complex, for most people, including people with learning disabilities; relationships obviously involve more than one person, each of whom can be more or less significant in different situations and circumstances.

Another Care Manager identified that younger families whom professionals were meeting at school, in the transition to adulthood stage, were receptive to, and even requesting, more individually focussed supports for their family member. This is evidence that different approaches – sometimes attributable to different generations having differing expectations and aspirations - were apparent locally, once again

reinforcing the importance of assessing on an individual basis or situation, and taking the time needed to maximise assessment skills.

Issues of support and available resources

Finally, Care Managers in Focus Group Two highlighted the issue of administrative support to individuals and families considering a direct payment; they explained the difficulties they had in understanding how direct payments actually worked until explained by the independent agency commissioned by the local authority to support recipients. Care Managers specifically referred to direct payments as a potential extra burden on those caring for a person with learning disabilities. There was a concern about the range and quality of supports available – one Care Manager was clearly of a view that traditional resources 'where you can see people are happy' were being disbanded, with few alternatives in their place. The researcher decided not to follow these issues up as they were questions of resources rather than relationships (the focus of this research). An informal discussion with the local authority Personalisation Manager, however, suggested that the local authority was aware of resource issues and working on them as part of its personalisation strategy. This raises the question of whether Care Managers are aware of the developments being undertaken by specialist units within their agency. Being aware of this work – and being able to contribute to it – could enhance their role and relationships with people with learning disabilities, and the effectiveness of the information and support Care Managers can offer to people with learning disabilities and their families.

5.5 Enabling Active Citizenship

As indicated earlier in this chapter people with learning disabilities identified three important attributes they wished to see in their relationships with professionals.

(1) Being treated with respect as an individual.

(2) Receiving good and reliable information about changes and new opportunities.

(3) Retaining ultimate control over any decisions made about their future life options.

Over of the course of the three Focus Groups participants amplified their understanding of these attributes.

Respect

Being treated with respect came across as an important aspiration for people with learning disabilities. It was most directly articulated by 04 on several
occasions but also expressed itself in a number of different ways during the course of the three Focus Groups. Being a beneficiary of respect had particular significance for people with learning disabilities when making important decisions and changes about their lives, not surprising perhaps, given that their experiences of relationships in the past might well have been based on dependency which, however caring in intent, puts the person in a devalued role. People with learning disabilities were able to identify what they perceived as the important ingredients of a positive relationship with others – in which they could feel respected.

In Focus Group Three, evidence of respect was articulated several times by both people with learning disabilities and Care Managers: 'He listened', said a person with learning disabilities when recounting the role play experience of applying for a direct payment with a Care Manager In Focus Group Three; and then: 'he told us what he was doing and why'. The Care Manager said of the latter two participants; 'I think they are capable people, they can work out problems for themselves'; and this was not only a reference to the qualities of the individuals concerned as well as their ability to call on the help of family if difficulties were encountered. Finally, coming back to Bayley's reference to the importance of 'reassurance of worth', when discussing choice and decision making in Focus Group Three, participants identified the increased control over decision making they had developed as members of Right Track. This was seen to enhance the degree of respect afforded members, particularly since it had developed into a Community Interest Company (CIC). This gave it common structures and processes with a variety of

organisations representing the aspirations of a wide range of community interests, not just learning disabilities; and it gave two members of Focus Group One the roles of Company Directors. Support was acknowledged, in the form of being provided with information and support, but decision making - the signing of important policies and documents, including authorising payments - was firmly in the hands of the person with learning disabilities. It would be possible to imply that working in line with social care values which respect the person is simple; it is not, as Braye and Preston Shoot (2003, p.37) point out, given that terminology can be vague and a firm value base difficult to maintain when subject to resource limitations and the multidimensional nature of statutory agency responsibilities. Additionally, Johnson and Walmsley (2010) suggest that approaches to people with learning disabilities are strongly influenced by western societies' longstanding preoccupation with the ability to 'reason' and 'reflect' as key determinants of human functioning (p.35). These are two concepts widely perceived as flawed in all people who have been 'labelled' with the collective description of learning disabilities. Essentially, the authors argue that when in a support role, people may be 'listening' to the aspirations of the person with learning disabilities but their interpretation of what they hear is overly influenced by the westernized cultural concepts of particular types of relationships. Examples are the beliefs about the status provided by employment, and perceptions of the role of an effective economic 'consumer' who values material goods. Significant here is the great importance attached to home ownership, foreign holidays, visits to the gym and cultural activity (p.41). These are beliefs that resulted in policies based on normalisation and access to 'ordinary lives'. Although these ideas had a positive influence on learning disability services, they did not acknowledge diversity; they also left power firmly in the hands of the professionals. Listening closely and reflecting on what people with learning disabilities are expressing – seeking to understand a variety of verbal, body language and maybe pictorial mediums - may reveal personal aspirations that do not always neatly fit the dominant value base of society.

For Care Managers time was a key factor if they were to represent the aspirations of people with learning disabilities[74] and to understand and address the sometimes competing needs of people with learning disabilities, families and support workers. They cited 'not knowing the person well enough' as the principal reason for them feeling 'insignificant' in the assessment or review meeting. In the relevant literature, Milner and O'Byrne (2002, p.261) draw wider attention to time as an issue in social work practice. They point out that assessment is time-rationed when it should be an on-going process, not a single episode. As Care Managers suggested in this research, not only might families or support workers have their own reasons for wanting a particular outcome from the meeting, but they were much more articulate than the person with learning disabilities. Consequently, a Care Manager, with limited knowledge of the person central to the assessment or review, could not judge whether the issues debated in the meeting reflected the views, or the potential strengths, of the person with learning disabilities.

The second key factor related to creative preparation – a communication tool - for a person's review, and is closely related to the extent to which the value base which underpins Care Manager's work is shared by other professionals in the social care field. A positive example, where a relationship based on respect had been used to prepare for a review, was cited by one of the Care Managers in Focus Group Two. 08 gave examples of schools and colleges where the creativeness of the material presented at the review, which had been developed through working with the person with learning disabilities over time prior to the meeting, was evidence that the views of the individual were being presented for discussion. The use of creative material to represent the views of a person with severe learning disabilities was also described by a participant with learning disabilities in Focus Group Three. This participant was aware of this through work undertaken as a member of Right Track to support a young person with severe learning disabilities and his father prepare for a review.

[74] To be an effective ally.

Good and reliable information

Throughout the Focus Groups there was a message that people with learning disabilities were seeking 'good and reliable information' as a critical factor in enabling them meet their aspiration to have more choice and control over the decisions made about their lives. For them, there were two aspects around information gathering: firstly, access to information that was *good and reliable;* secondly, participation in gathering it by working as closely as possible with professionals and others. There is a natural human wish for any change in our lives to be as simple and as smooth as possible, and participants in these Focus Groups shared that wish but, for them, 'reliable' implied 'accurate'. If processes were not clear, deadlines for completion were a risk, or if an agenda item at a Partnership Board[75] was about giving information rather than consultation then that should be made clear. There should be clarity about the problem, and its source. When this principle is not adhered to, there is a danger that people with learning disabilities will feel confused and that the failure is wholly personal rather than organisational.

A Care Manager, in Focus Group Two, highlighted the problems that can be encountered around information in situations such as projects to close hostels and move people into community accommodation. Purchasing land and building development can present a whole range of delays, especially where time-scales have been overly optimistic. Another challenge to meeting people with learning disabilities' request to be provided with 'good and reliable information' can arises when opportunities for new types of day time activity are presented as providing more choice – something people with learning disabilities aspire to – but, if that involves the closure of a day centre in order to liberate funding, information becomes complex and choice

[75] The example of the Partnership Board had arisen when 02 and 04 had talked about their experiences of chairing Partnership Boards. Often Partnership Boards cannot make decisions because legally the decision rests with a local authority Manager, or a Committee. People appreciated that there were legal rules of delegated authority decision making and wanted the agencies to be clear about this when agenda items come to the Board.

may have loss, as well as gain. These situations need careful thought and preparation and, as 04 once said in a meeting with the local authority concerning the funding of Right Track, at which both the researcher and one of the advocates were present: 'we are not delicate flowers; we can take bad news.'

Retaining ultimate control over decisions

A powerful message of the role-play in Focus Group Three was people with learning disabilities can work together with professionals to gather information that can be used as the basis of choice for the former. Working together could mean using the Internet to gather information or going out to see things. As an example, when talking about her work in the role-play looking at 02's aspiration for a holiday paid for from a direct payment, the Care Manager (08) talked about her work with other people with learning disabilities who had wanted to explore the options of a holiday abroad. Her experience was that a great deal of practical information regarding holidays can be gathered by using Google for example, while a joint visit to an airport gives the person with learning disabilities the experience of the organisation of the airport and how busy and bustling it is. This provides the person with learning disabilities with information they can conceptualise which, in turn, may lead to a decision to do things in a different way, or even decide against taking a holiday. Rather than simply being told about the difficulties, or having the decision made for you, this is a process much more akin to the way other people make decisions. It was further noted that if the Care Manager commissions the 'information gathering' and support from another source, there is a break in the continuity of the information and decision making processes that risk losing touch with the essential values underpinning the process.

Models for future relationships

Two concepts are recommended as models which could be developed to enable active citizenship for people with learning disabilities in the twenty-first century.

Firstly, ecological theory (Bronfenbrenner 1979) can provide Care Managers (Walker and Crawford 2010, p.22) with a framework for examining individual action, but in a way that also takes account of the impact of close family and friends, and the wider community and environment, upon the expectation and experiences of the individual person. This framework also takes account of how the passage of time impacts on people's lives and the environment in which they are living. Such an approach does not see an individual who is 'at risk' and in need of 'services' but places that person in a social context and considers their interaction with others; this does not disempower and constrain the individual, but opens up the possibility of joint action and personal development. Ecological theory has been used to offer an alternative perspective on the sexual vulnerability of people with learning disabilities (Hollomotz 2011, p.38).

Secondly, co-production[76] is underpinned by a belief that people who use services do not just have needs, they also have assets: skills, expertise and mutual support that can bestow additional quality on a service (SCIE Research Briefing 31: 2009). Co-production is a theme that has re-emerged after a relatively brief life in the 1970s. Recently, personalisation has been adopted by government across all aspects of its service delivery. Its evolution began in social care – the underlying concepts inspired initially from the campaigning of disability groups for greater independence for themselves through changes to traditional service-based support, such as direct payments – and encompassing notions of self-directed support and individual budgets referred to in the earlier part of this chapter. Participation and co-production are a means to challenge the longstanding paternalism that is held to have been a feature of social care, providing a new dimension to the relationships that exist between those (professionals and service users) who are participating in this act(s) of co-production.

In addition to the two concepts outlined above two organisational issues require consideration. First, there is the question of training. There is a perceived imbalance

[76] See footnote 9, page 100.

between Care Managers' value base and other strata of social care staff. The three year degree courses that are now the foundation of both social work and nurse training provide recipients with the most comprehensive training available in the social care field and then post qualification training. Other staff might not need, or be capable of undertaking that training, but their value base, and understanding of the principles underpinning social care, should be commensurate with their level of impact on the lives of people with a learning disability, which is often a daily, and very personal, intervention. The current search for new staff roles, such as brokers, is valid in terms of seeking new skills in order to link to housing, education, leisure and employment opportunities but they, too, will need strong underpinning value base in respect of their understanding and perceptions of people with learning disabilities; otherwise they may contribute to process, but add little to outcomes.

The second organisational factor concerns the issue of how well different local authority 'divisions' are integrated around the needs of people with learning disabilities and the personalisation agenda. Specifically, at what level does horizontal communication take place and how effective[77] is it? Three professionals provided evidence that part of their 'ally role' to a person with learning disabilities was their knowledge of local providers with whom they had 'personal relationships' which contributed (jointly with provider staff) in developing options for people with learning disabilities as well as a track record of delivery based on the principles of Valuing People. Care Managers were less confident that other agency roles, such as contract compliance, inspection and market development, were equally vigorous. This does not mean they are not vigorous, but that Care Managers were not well-informed on these processes, or how their knowledge could contribute to them. This viewpoint links to the suggestion in the literature (see, for example, Hafford-Letchfield 2007, p.17) of negative outcomes stemming from the 'fragmentation' of service delivery, as the assessment of need has been separated from

[77] What mechanisms are used for communication.

the provision of services. It also links to some expressions of concern by social workers in relation to personalisation and an increase of non-qualified staff (Dunning 2012).

Finally – as the literature search identifies - *Valuing People Now* (2009) is clear that person-centred planning is a key process for achieving people's aspirations, and making a reality of rights, independence, choice and control. The literature also makes suggestions as to how this process could be improved. A link between that literature and this research is suggested in the final chapter which outlines the conclusions.

6. Conclusion

6.1 Introduction

The research set out to explore the reality of rights, independence, choice and inclusion for people with learning disabilities. The subsidiary question relates to the role of professionals (using Care Managers as a model) as allies to people with learning disabilities. Individualised funding provides the backcloth to the research as it provides one means for people to achieve their aspirations for the future within the framework of rights, independence, choice and inclusion set out in *Valuing People* (2001). It extends the choice available to people with learning disabilities by offering the opportunity to go beyond the framework of specialist services that have been a large part of their lives in the second half of the twentieth century; and this is particularly true of the generation included in this study.

Relationships – how professionals engage with people with learning disabilities and the importance they place on an individual's aspirations – is of at least equal importance to the more frequently focussed upon elements of social care policy, such as funding and market development. Factors that encourage the full participation of people with learning disabilities in any discussions about their lives, and futures, have been identified in previous research, but the evidence of *Valuing People Now* (2009) is that they have not been effectively acted upon. Overall, the limited progress identified in *Valuing People Now* (2009) for people with learning disabilities is disappointing.

The personal stories of the participants in this research are encouraging, although an evaluation of the evidence should take account of the potential limitations of research with a small group of people who may be seen as representing more able people with learning disabilities. The possibilities of bias exist with both 'local' and 'insider research'. Nonetheless this thesis is arguably effective in illuminating both the issues people with learning disabilities can face, and the potential for local action. A key requirement is

reflexivity from all professionals involved in projects and initiatives so as to maintain a focus on the expressed wishes of people with learning disabilities.

I argue that the principles of support expressed in this research can be equally applied to people with more profound disabilities, albeit that both more time, and innovation, may be required to meet differing individual needs. The ways of recording people's personal history and aspirations adopted in this research, and Care Managers' references to the potential for making creative inputs into review meetings, indicate possibilities for positive future action; whilst the shared information gathering between Care Managers and people with learning disabilities, and advocates, in the role-play in Focus Group Three, offers further ideas on the way forward.[78]

6.2 Competing agendas

The potential impact of competing agendas on the needs of people with learning disabilities was illuminated during the course of the fieldwork for this research. The effort to organise Focus Groups in a way that was empowering for people with learning disabilities, and to take account of the work pressures on the ALDT, proved challenging and time consuming[79]. Additionally, in Focus Group Three[80], the facilitator struggled at times to keep the needs of people with learning disabilities to the fore; it was easy to engage in a dialogue with the professionals about social work aspects of the issues being discussed, (as opposed to the view point of people with learning disabilities), and there was the imperative to meet the academic requirements for the research which raised distracting levels of anxiety. Reflecting on that Focus Group afterwards the researcher could see how other agendas challenged the neutral role of a facilitator, and how personal 'power' could easily be used to shift the focus of the session. Again, this highlights the importance of reflective practice.

[78] See Ecological Theory and Co-production p.110.
[79] Third (joint) Focus Group almost proved impossible to arrange.
[80] This was a joint Focus Group involving people with learning disabilities and Care Managers. The researcher managed learning disabilities in the County until his retirement in 2006.

6.3 History: linking past present and future

This thesis suggests that relationships, and the ways in which people with learning disabilities are enabled to consider choices (Aylott 2001, p.512), is an important factor if they are to achieve their aspirations and be supported appropriately to do so. Johnson and Walmsley (2010, p.35) content that western societies' longstanding preoccupation with the ability to 'reason' and 'reflect' as a key determinant of functioning as an efficient and successful human being results in a persistent perception of people with learning disabilities as different. In this way, they continue to be marginalised long after the draconian legislative framework of the 1913 Mental Deficiency Act has disappeared from the statute book.

The influence of the past was significant to people with learning disabilities who participated in this research; and there was a strong association with the traditional service model that has supported people with learning disabilities and their families since the 1971 White Paper *Better Services for the Mentally Handicapped.* The symbolic significance of traditional services, representing a fight for rights and support (by post-war parents), might be underestimated when such services are seen as a source of funding for new developments. Buildings and service models may be seen in terms of financial costs; from another perspective they represent personal history, sources of friendship and security not readily apparent 'in the community'. A particular generation (people with learning disabilities and their families) are being asked to give up a lot. What may appear as 'recommissioning' from a professional perspective may appear as 'decommissioning' to those who feel they have the most to lose.

Apart from 02, day centres have been important in the lives of 01, 03, 04, 05 and 06. Although 04 and 05 have not attended a day centre for some years, working with 03, they have been very involved in Right Track's work for the local authority in talking to people with learning disabilities about personalisation. 04, for example, has many positive memories of his time in day services – working in the laundry – and his

experiences[81] contrast with the predominantly negative view of people with learning disabilities segregated by specialist services. In consequence, people in this position can face difficulties in transferring any practical and social skills learnt in a day centre to the world of paid employment. A key message the three have picked up in their Right Track work are people's concern that 'choice' might not include the choice to remain in a service that has been a key part of people's lives, resulting in loss of friendships and valued support.

Including 01, a total of four of the six participants indicated the important role of families in their lives; 01 talks of his mother teaching him how to do housework; an important skill now that he lives alone. It is not unreasonable to speculate that parents of this generation of people with learning disabilities might, in the past, have had to explain why a son or daughter went to a day centre, as opposed to the school, college or work that was important in the lives of siblings, and other young people in the street or neighbourhood. Additionally, the difference would be explained in positive terms, citing the benefits they provided to the person attending. Policy changes at a personal level may appear to challenge the advice and explanations provided by important and influential people in the lives of people with learning disabilities; for example, the discussions in Focus Group One provided some insight into the impact of the death of parents. Apart from the emotional bonds common to the majority of people, there was a strong link to the parental role in making decisions and providing guidance. 03 and 04, and later 01, responded to this loss of parents, and home, by taking on the challenges of being tenants of their own properties, rather than going into residential care, not an easy task for anyone. The 'voice' of their parents continues to come through as part of their expressed opinions.

These accounts throw a different perspective on policy changes. New policies are perceived as progressive and challenging longstanding disadvantage (Burton and Kagan

[81] He said going to the day centre in 1967 'gave him a purpose'

2006, p.300) by making attractive promises of rights, independence, choice and inclusion which present as both enticing and liberating. This then leads to a justification for the closure of an expensive resource[82] to fund the benefits of new policies which, in turn, set up the need for targets and performance indicators. Such a process may well be an inevitable part of the process of local implementation. This research suggests the need for awareness of another perspective: recognising that change needs to be sensitive to the link between past, present and future involved, and its impact on the people at the centre of that change.

At one level, the change process should consider[83] how personal history is to be preserved as change occurs (Taylor 2003, p.ix). People with learning disabilities[84] could be encouraged to record (through discussion, video, use of graphics and pictures) their own history and connections with the 'service' that is to change. Just as memories of buildings can be preserved through pictures and videos, the discussion this entails will also illuminate what has been important to people. Alongside memories of buildings and people, important but otherwise intangible themes will emerge and should steer planners and participants involved in the change to reflect how notions of friendship, support acceptance and safety can be incorporated into new plans. The choice to stay at 'the day centre' may not be possible for policy and economic reasons. People with learning disabilities, and their families, may cope better with change, and perhaps embrace it, if they are helped to understand the process of change, that is, what was said or done thirty years ago is not necessarily wrong, more, it is connected to the past and future. If the underlying values of past services can be identified in the new models, connections are made; new opportunities go hand in hand with important aspects of welfare citizenship: the rights to protection, good health services and appropriate

[82] Such closures are likely to have the greatest impact older people with learning disabilities and their families for whom services such as day centres have been the mainstay of family support.
[83] Involving those central to the change process.
[84] The research suggested a close link between service users and staff so there could be benefits to joint working providing the needs of staff did not dominate the themes that emerged.

support. The call is for these aims to be sensitive to the needs of people with learning disabilities and their families.

6.4 Models of support

The people with learning disabilities in this research identified (1) being treated with respect; (2) receiving good and reliable information; and (3) retaining control of significant decisions in their lives as the benchmarks of valued relationships with others which could support them in developing aspirations for their future lives. The views expressed by Care Managers implied they felt competent to meet the expectations of people with learning disabilities; and the research identified two key roles for them when making an assessment or undertaking a review. Firstly, as an ally, they would be advocating for the person with learning disabilities; secondly, their role (when taking formal assessments or reviews to a senior manager or panel for funding) involved acting as an interpreter and translator of the aspirations of the person with learning disabilities. In both of these roles, a critical element is 'communicating' the strength of feeling and enthusiasm the person with learning disabilities has for their particular aspiration but also seeking to incorporate into formal documentation the service user's preferred communication method (graphics, video or IT presentations as examples).

It was the evolving model of working with people with learning disabilities nurtured in Right Track that influenced this research. Right Track is rooted in an advocacy model which seeks to empower people with learning disabilities. Since its inception[85], it has sought to provide people with learning disabilities with information about the opportunities enabled by direct payments and to feedback to the local authority the issues that people with learning disabilities face, primarily with direct payments, but other issues as well. The work continues, but now embraces a broader perspective of personalisation. The other key development has been to establish Right Track as a Community Interest Company; this is registered at Companies House and follows

[85] 2007.

national regulations for business and financial reporting, the latter requiring the services of an accountant. Two people with learning disabilities (03 & 04) are the Company Directors and are legally responsible for business activities and signatories for all business documents. Two volunteers support the directors in all their activities, and a part-time assistant manages administrative work and diary planning. Monthly meetings are held with local authority representatives to monitor the working being undertaken.

A recognised company structure[86] gives people with learning disabilities legal roles and responsibilities that are established by a regulatory authority for all businesses. The unique selling point of this 'business' is the value of the directors' experience of having a learning disability and their ability to communicate with, and represent, the views of other people with learning disabilities around the opportunities and support people with learning disabilities aspire to in pursuing their aspirations for the principles of *Valuing People.* From a business evaluation perspective, the major cost to the business is the financial cost of transport (taxis, trains, buses and mileage reimbursement) that is vital to ensure the directors are able to be present at all the key meetings and projects in which the organisation is involved. The other cost is one of the time and resources put in by two volunteers who support the company directors in business decisions, communications and project management. One key principle of the business is that few, if any, business directors, perform their role without the support of specialist advice and support, particularly in financial management; people with learning disabilities are no different. The second principle is that the directors are provided with information and advice, but they make the decisions and also learn by experience.

The demand on resources (volunteer support) is considerable, but is commensurate with the satisfaction and feelings of worth experienced by the directors, and a few other people with learning disabilities involved in projects. The financial costs are small. On the deficit side, it has not proved easy to involve enough people with learning

[86] Community Interest Company (CIC).

disabilities to take on all the work the organisation could undertake; the aim of providing work (perhaps part time) has not yet been realised. The volunteers are aware of the thin divide between offering advice and information and heavily influencing, or even making decisions on behalf of people with learning disabilities. Almost every time the business engages with new people there is a need to remind those people that business is done through face to face contact with the directors, not by talking to the volunteers. Equally, there is an imperative not to suggest that choice is available when, in fact it is not. The test always is: did the process for making a decision empower the directors (people with learning disabilities) and was the final decision made by them - however time consuming that might have been – no shortcuts!

6.5 Valuing People

The critiques of *Valuing People* (2001) furnish us with useful insights for the future. It has been suggested that *Valuing People* (2001) offers a romantic concept of choice, based on modelling learning disability on those with the least impairment; thereby underplaying the support needed if inclusion, autonomy, good health and meaningful activity is to be a reality in the daily lives of people with learning disabilities (Burton and Kagan 2006, p.305). Extending choice beyond a fixed menu of existing services for people with learning disabilities poses challenges for social care commissioning.[87] This research has not ignored the economic issues in making choice a reality. Rather it explores the choices aspired to by a small group of people with learning disabilities living in a local environment, proposing that understanding people's individual aspirations – and their expectations of professional support when exploring those options – contributes to *Valuing People Now* (2009) expressed intention 'to make it happen for everyone'.

[87] for example, finding ways to release the investment in traditional services in order to develop new market opportunities.

Learning Disability Partnership Boards were given responsibility for those elements of the Government's proposals which relate to services for adults with learning disabilities (*Valuing People* 2001, p.107). People with learning disabilities (and carers) were to be key members of the Boards; the latter were to be a powerful catalyst for change as they engaged with a wide range of public services to produce strategies and frameworks to ensure better opportunities for people with learning disabilities (Fyson and Ward 2008, p.2)

Person-centred planning, or person-centred support, was the core of *Valuing People* (2001). If this concept is not understood and embodied in the partnership function of LDPB, and in the individual interaction between professionals and people with learning disabilities, the chances of developing services that embrace the principles of rights, choice, independence and inclusion are remote (Fyson and Ward 2004, p.3)

Learning Disability Partnership Boards

The determinants for a successful Learning Disability Partnership Board, set out in *Strategies for Change*, have been around since 2004. This checklist cannot really be improved upon so, acknowledging its authorship it is reproduced in Appendix 7. Revisiting the organisation of the local Learning Disability Partnership Board would be a crucial stage in addressing the issues raised by people with learning disabilities in this local study. Both Norfolk (Norfolk Learning Disability, 2013) and Coventry (Coventry Partnership, 2013) are two current examples of active, well structured Learning Disability Partnership Boards.

Person-centred planning

PCP remains a key tool for meeting the needs of the individual person with learning disabilities (*Valuing People Now* 2009). Robertson *et al* (2007 p.297), cites the lack of trained facilitators and failure of services to give staff time to plan as two significant

causes for person-centred planning processes not achieving desired outcomes for people with learning disabilities. Trained PCP facilitators in the local setting described in this study would potentially introduce the skills to manage the competing interests that can legitimately arise in a person-centred planning meeting. In addition, creating longer timescales for preparation and for assessment and reviews would give Care Managers the opportunity to get to know the person with learning disabilities, and (as an ally) ensure that the person's personal aspirations are heard; likewise staff would have more time to develop creative ways to record those aspirations and bring them to a meeting.

6.6 The Future

With a new government there is arguably less of a focus on the specific needs of people with learning disabilities, which appears to have been replaced by a personalisation agenda with a generalised approach to all users of social care. Simon Duffy (2012, p.111) makes the point that personalisation, by itself, is not a single solution and urges that we do not forget its building blocks: independent living, direct payments, supported living, person-centred planning and individual budgets are the keys to citizenship rather than reliance on personalisation by itself. Without that 'deeper understanding' the reality of the principles set out in 2001 will continue to be elusive. There are balances to be struck, for example, empowerment and safeguarding are not opposites, both need to be integrated into professional practice recognising that people with learning disabilities have an equal need to be supported to develop friendships as they do to understand the dangers (Williams and Evans 2013, p.96); secondly, moving from 'services' into the community requires people to develop new skills, otherwise professionals continue to care (rather than support), and it is only the 'bricks and mortar' that change; thirdly, learning disabilities services have failed in the past to recognise the weaknesses of the 'readiness model' where people find it difficult to transfer skills taught in one place on moving to another setting (Rooney 2002, p.86). New skills are not just practical, relationships are important and require a very broad range of skills; and the case is well made that these best come from a perspective of education rather than protection

(Hollomotz 2011, p.167). The importance of safeguarding is not diminished by calls for a more creative approach to risk; if there are to be new opportunities for people with learning disabilities then being flexible, pursuing the 'new' and the 'different' (Seale and Nind 2010, p.172) has to sit equally alongside the learning from inquiries and serious case reviews. In Focus Group Three, professionals and people with learning disabilities worked together in a person-centred approach - education and learning were often a shared process.

Very recent literature seeks to embrace the concept of 'access' for people with learning disabilities. Access is presented as complex for those whose history has been one of exclusion or segregation; people whose lives have been built around family, residential services or day services face a real challenge, which may require long term support if they are to access public spaces, shopping centres libraries and supermarkets. It is not just a question of the physical access (Abbott and Detheridge 2010), but of the strategies, skills and support that encourage both interaction and personal safety. The journey of access may start with information and then go on to specifics, such as primary healthcare, leisure, mainstream education (Seale and Nind 2010, p.5). Access cannot be generalised, it has to be tailored to the individual and the authors make the important point that access to one area is not a guarantee of access to another area. In the same book, Walmsley (2010, p.23) illustrates complexity in terms of accessible language; often seen as a key starting point to access and inclusion. In the process of producing an accessible version of Valuing *People* (2001) the four principles are reduced to 'citizenship', but citizenship is both complex and abstract. Translating abstract concepts in accessible language requires considerable skills in itself, and Walmsley poses the question: have we been guilty of seeing the production of accessible versions (for example agendas and minutes of a Partnership Board) as evidence of achievement rather than pursuing the complex issues of understanding and participating in Partnership Boards more fully? Recognising the rights of people with learning disabilities to information and access is a critical political achievement, in making it a reality the

individual person with a learning disability will need allies – people who value reflexivity in practice and can provide determined, skilled support.

Appendix 1

Self-directed support

Self directed support is an approach to social care, developed by In Control, which gives people optimum choice and control over their support arrangements. The individual controls the money and how it is spent to meet their needs and aspirations. There is help available to do this, and families, advocates and independent brokers, can help in making choices and decisions. Self directed support aims to promote independence, health and well being.

Sources: SCIE Guide 10: Direct Payments: Answering frequently asked questions.
SCIE Research briefing 20: The implementation of individual budget schemes in adult social care.
In Control Website

Direct Payments

Following persistent campaigning by disabled people, the 1996 Community Care (Direct Payments) Act came into effect in April 1997. This gave local authorities in England, Wales and Northern Ireland the power (but not the duty) to make direct payments.

In April 2003, regulations came into force that required councils in England to offer direct payments to all people assessed as eligible for social care. A direct payment can be used to purchase services from the private or voluntary sector, or individuals can employ their own staff. It cannot be used to purchase public sector services. Direct payments were the first initiative to promote control for people using adult care services by providing a means to move away from the traditional services models of care.

Individual or Personal Budgets

Individual Budgets, now generally called personal budgets to distinguish them from the individual budgets of the pilot schemes which were intended to draw several funding streams together by contrast with personal budgets which related only to adult social care funding. The basic concept is that the individual person should know, from the start, how much money has been allocated to meet their assessed need, and allowing them as much choice as possible over how that money is spent, and as much control over the process as they want. The local authority retains primary responsibility for ensuring an appropriate range of support is available, and uses a Resource Allocation System (RAS) to distribute funds transparently. Unlike a direct payment individual budgets can be managed in different ways:

- By the individual as a cash direct payment
- By the care manager
- By a trust
- As an indirect payment to a third party
- Held by a service provider

Appendix 2

Right Track Information Services CIC

About Right Track[88]

Right track is a Community Interest Company (CIC) run by people with a learning disability for people with a learning disability. We are working to support people with a learning disability in *******. We became a CIC (in 2011) to be more independent, and this gave us confidence and helped us to understand how to run a business and the support and information we needed to do this. Our two directors are people with a learning disability. We now have much more freedom to manage the company and make decisions about what we do. We have a lot of support from volunteers and from the local authority.

CIC Objectives

[88] To meet confidentiality requirements this is an edited extract from Right Track's business plan

- To empower people with a learning disability through support, information, networks and resources
- To help people and organisations that support people with a learning disability to have a better understanding of their needs
- Provide opportunities for people with learning disabilities to gain experience and skills through working with Right Track or taking part in running the company

What we do

- Produce Easy read documents to clear and accessible information about local consultations, personalisation and other changes to health and social care
- Run workshops to help people understand personalisation and personal budgets and think about how they could use them
- Provide drop in support, workshops and accessible information for a project where people are trying out personal budgets
- Attend the Learning Disability Partnership Board meetings
- Seek to raise the profile of people with learning disabilities

Outcomes

People with learning disabilities know more about:

- Running a company and taking on responsibilities
- Right Track and their work
- Personalisation and personal budgets
- The local authorities plan for learning disability services

The Council and people who run services for people with a learning disability know more about:

- Right Track and their work
- How to involve and communicate with people with a learning disability

- What support people with a learning disability need to understand personalisation and personal budgets
- What is important to people with a learning disability and what they and their families think about the local authorities plan for learning disability services

Families and carers know more about:

- Right Track and their work
- Personalisation and personal budgets
- The local authorities plan for learning disability services

Social work degree students know more about:

- Working in partnership with people who use services

Appendix 3

Information provide to participants

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(Easy to read version)

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What does being a Citizen mean? 9

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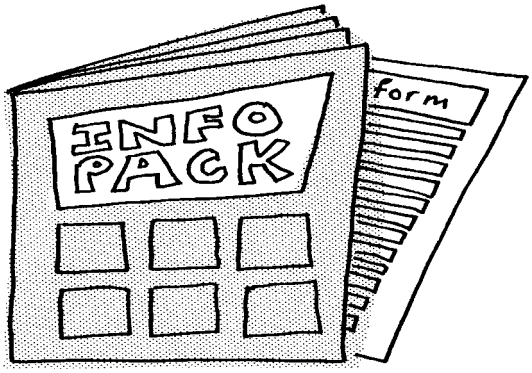


1: Introduction

This section of the folder explains how my research project has developed since I last met people back in November 2008.

It explains the overall aim and the objectives of the research.

It describes how I will be undertaking a literature search to see what other people have written about the areas of my research, and how I will talk to people in Bedfordshire through Focus Groups to find out their experiences and opinions.

There is a lot of writing in this folder because research has to be explained carefully to everyone. Here are some 'tips' to make reading and understanding easier.

2. Helpful Tips on understanding what the research is about having support to speak at the Focus Groups

✓ Some people may find pages 3-6 hard to read so the rest of the folder is an 'easy to read version'.

✓ The folder is divided into sections, **on different coloured paper**, so you don't need to read everything at once – read a section at a time.

✓ At all meetings we will start by talking about what we are going to do, and make sure everyone is clear about what is going to happen in the Focus Group before we start.

✓ You will have an advocate at the Focus Groups to help you understand what is being said and to help you to speak for yourself. You can also contact them in between meetings if you want to talk, or have any concerns.

3. How to contact me directly if you want to ask any questions about the research

- ✓ If there is anything you don't understand, or you have questions, here are people who can contact for help:

John Presland 07785 542 976

(Add other names and contact when known

Research Summary

I met with both people with learning disabilities (Right Track members) and then the social team in November 2008, to discuss my initial ideas, where we broadly agreed that people wanted to participate. Since then I have been working on a specific focus for the research and I am now in the process of formally applying to the Research Graduate School at the University of Bedfordshire to be accepted to undertake an MA in research.

As part of this application I am developing an information pack for the social work and the group of people with learning disabilities who are connected with Right track.

The alternative information I have provided is in a 'easy read' version and both 'versions' will be available to all Focus Group members and anyone who is supporting the research process in order to ensure equity in the communication process. I also want people to be aware that participation is a voluntary for every person and there are no negative consequences if you decide not to take part. Equally, at any stage of the research, you are free to withdraw, if you feel that is right for you. Other work includes the important point developing the ethical framework for the research. Once approval has been granted I will be able to formally proceed and work to a planned timetable for the literature search, three focus groups and the write up.

Aims & Objectives:

The aim of this research is to identify what contribution direct payments[89] can make to supporting rights, independence, choice and inclusion for

[89] This was later amended to explore the reality of rights, independence choice and inclusion in the lives of people with learning disabilities. The emerging agenda of individualisation, and then personalisation, was seen as a backcloth rather than the centre of the research.

people with learning disabilities; these represent key principles in Government policy on this service user group, as set out in *Valuing People* (2001, p.3). This White Paper contains a statement that legislation which confers rights on all citizens applies equally to all people with a learning disability, linking these four principles to the concept of citizenship (2001, p.3).

Specific objectives:

i. To evaluate whether the use of direct payments for people with learning disabilities makes a reality of the principles of *Valuing People* (rights, independence, choice and inclusion) and supports them to be defined as full citizens;

ii. To model the role of professionals as 'allies' and identify those principles underpinning their working relationship with people with learning disabilities which optimises access to direct payment and the development of full citizenship.

Methodology: The research is based on the ontological approach of constructionism (Grix 2004, p.18) in order to foreground the interaction between the social actors involved. This links in turn to an epistemological perspective of interpretivism (Bryman 2008, p.13), which involves a need for the researcher to understand the subjective meaning of social action between people. Central to the research question is the relationship between people with learning disabilities and professionals; an interpretivist approach allows significant social interaction between these actors to be identified and explored.

The first stage of the research will be a detailed systematic literature search (Hart 2005, p.154), Issues of power and empowerment are central. The review will explore the impact of ideas of dependence, independence, autonomy and interdependency on policy and practice for people with learning disabilities using a critical historical analysis, beginning with the 1913 Mental Deficiency Act through to Valuing People (2001) and Valuing People Now (2009), to explore how disability has been conceptualized and re-conceptualized over time. This analysis will illuminate the negative perceptions of learning disability that have existed over time, and where legislation has failed to address these perceptions. This will enable me to explore with people with learning disabilities and professionals how these negative perceptions might now be jointly addressed. Direct Payments will be used as focus for exploring the reality of the key principles of *Valuing People* because of their stated purpose: '*to give people control over their own life by providing an alternative to social care services provided by a local council' (*Department of Health: 2003).

Stage two of the research will be three group interviews based on a focus group approach: (1) people with learning disabilities using, or wishing to use, direct payments; (2) staff in a learning disability social work team; (3) a joint service user-professional group to explore the themes that emerge from the first two groups, highlighting similarities and differences in expectations on ways forward for future working relationships and associated issues of power and power sharing.

A focus group approach is to ensure a 'spotlight' on the specific subject of direct payments for people with learning disabilities' aspirations and the relationship/support they might need to access them. Bryman (2008, p.473) explains that this is an alternative to 'group interviews' which normally cover a range of subjects.

Finally, the study aims to synthesize and evaluate the combined evidence from the literature review and the focus groups to construct a new concept of interdependence and professional allies for people with learning disabilities as a means of supporting them with their aspirations.

People with learning disabilities often find language and reading difficult. To address any potential power imbalances they will be provided with independent advocate support to help them understand issues, and decisions they need to make in the research process. Pictorial methods of recording will be used, and group ground rules with which this group of people with learning disabilities is both familiar.

The final report will be anonymous so participants will not be identified although I recognize that participants may recognize the views of themselves and others known to them because of the close networks we are connected with in Bedfordshire and the services available for people with learning disabilities. During the research all data will be kept secure and destroyed once the final report is completed.

Proposed work & time Plan:

Context: Concerns about the take up of direct payments by people with learning disabilities led to a special review commissioned by the Government. Recommendations were made about overcoming

generalized perceptions of people with learning disabilities and their ability to make choices (Direct Choices 2004, p.iv). Additionally, the review of *Valuing People* (2001) notes that, eight years on, the principles and aspirations for people with learning disabilities are still not a reality for everyone (Valuing People Now: 2009).

An initial literature search has identified the challenge presented by the social model of disability to the dominant medical model as an approach which illuminates the place of disabled people in society. The medical model outlined by Drake (1999, p.10) has been challenged by a vocal activist movement (Oliver 2004, p.7) seeking to move disability from an individual responsibility to a societal responsibility for accommodating impairments within its structures. An additional debate asks whether people with learning disabilities are fully included in the social model of disability (Chappell 2008, p.213) suggesting that those activists who have done so much to argue for the social model of disability exclude 'intellectual' impairments.

Professionals have traditionally been very influenced by the medical model of disability; when arguing for independence for people with disabilities, tend to have a professional concept of independence based on overcoming functional disability, whereas advocates of the social model conceptualise autonomy in terms of rights, access and control (Goble 2006, p.42).

Expected results: This research will explore the implications of the professional perception of people with learning disabilities for accessing direct payments. In terms of empowerment the study

aims to identify the value of a notion of 'professional allies' for people with learning disabilities seeking to gain control over their own lives – a relationship which acknowledges 'interdependency' rather than the traditional opposing concepts of dependency or independence. This research focuses on direct payments specifically but will have relevance to the Government's current agenda for the transformation of social care. (Putting People First, 2007).

In terms of a time plan the following is proposed:

Sept 09-Mar 10:	Detailed literature review building on knowledge generated in the indicative literature search; Negotiate dates for three focus groups;
Apr 10:	Developing research instruments.
May 10-Sept 10:	Focus groups and recording
Oct 10-Aug 11:	Analysis /write up

John Presland
07885 542 976
john@presland24.fsnet.co.uk

2: What is this research about?

My name is John Presland I study research at the University of Bedfordshire.

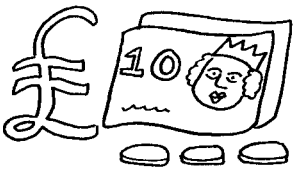
If you need to contact me:

- Mobile 07785 542 976
- Email: john@presland24.fsnet.co.uk

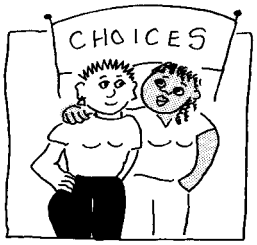
My research is about people with learning disabilities, and their experiences of direct payments and being a citizen.

Then I will compare this with what has been written in *Valuing People* and *Valuing People Now* say should happen.

What are Direct Payments?



Direct Payments mean people receive money instead of services.



This should give you more choice and control over what you do, and who supports you.

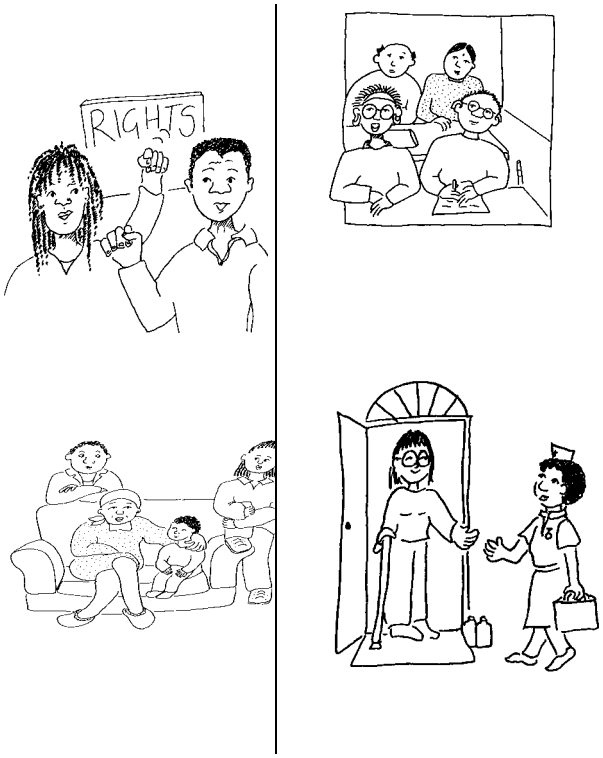
Here are some of the questions I want to ask you about Direct Payments

? Can Direct Payments help you to change the way you live, for example, what you do in the day or evenings?

? Can Direct Payments help you to feel more in control of your lives, and more able to make choices for yourself?

? What help do you want from professional people, like social workers, to get a Direct Payment and then to manage it, but still be able to make your own choices?

What does being a Citizen mean?

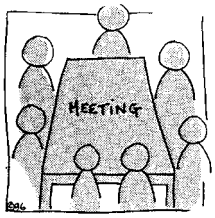


Freedom and the right to make choices;

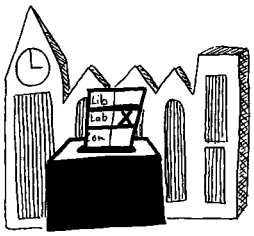
Having support in your life to:

- Enjoy family life;
- Live independently;

- Learn new things through access to education with other people;
- Enjoy good health;
- Being safe;



- having access to information and services;



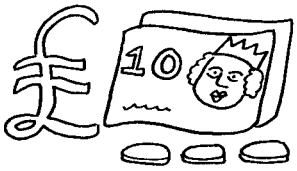
- Being involved in public life;

? In my research I want to find out if Direct Payments can help people with

learning disabilities

to become full citizens.

3: I want to talk about these questions by having meetings



1 meeting for people with learning disabilities;

1 meeting for social workers;

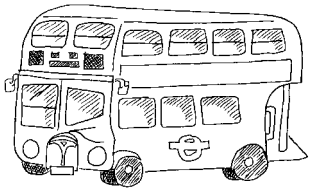
1 meeting for people with learning disabilities and social workers;

The meetings are called **Focus Groups;**

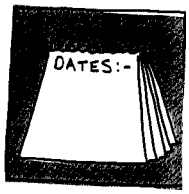
A focus group is a meeting where we talk about one subject – **Direct Payments** and if they help people to become full citizens;

About the Focus Group

somewhere you know.



Let us know if you think travelling to the meeting might be a problem.

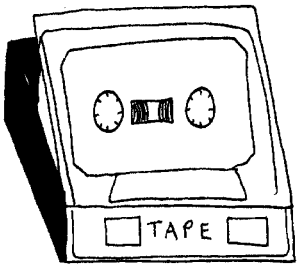


The meeting will be held

We will try to agree a date for the meeting that is OK for everyone.

We will use traffic light cards to help everyone understand what is happening, and be involved. Advocates can support you at the meeting if you want help to understand things, and to help you speak up.

You decide whether you want to join the Focus Group & you can leave the meeting at any time you want to.



If you are happy with all this I will ask you to sign a form to say you agree to be in the group.

These forms are called **Consent Forms.** If you want help to sign these **Advocates** can do this, or you may have **friends/family** that will help you.

What we say at the meetings will be recorded and written down. You can see a record to check I have written down what you said correctly. One version of the reports will have lots of pictures to make it easier to understand

4: After the Focus Groups

I will make recommendations about good ways of helping people with learning disabilities who want to use Direct Payments to make a difference to their lives.

I will not use people's names in the report and written notes will be destroyed after the report has been written.

I will write a big report about what I have read, and what you have told me in the Focus Group.

But I hope people will read what the group has talked about.

Maybe people will want to talk to you later about	managing Direct Payments differently in the future.

5: Consent Forms

CONSENT FORM 1: (Put meeting date)

(1) I have read leaflet about the Focus Group where people with learning disabilities talk about Direct Payments

i. *I want to join in*
ii. *I do not want to join in*
iii. *I would like an advocate to explain this again to me before I decide*

and

iv. *I understand I can change my mind at anytime*

Name……

Date……

Advocate Support: (if requested)

I confirm that I have talked to ……about the research project on Direct Payments. I believe they understand the nature of the project and have said

i. I want to join in

ii. I understand I can change my mind

iii. I do not want to join in

Advocate

Name……Date……

CONSENT FORM 2: (Put date of meeting)

(1) I have read leaflet about the Focus Group where people with learning disabilities and social workers talk about Direct Payments

v. *I want to join in*

vi. *I do not want to join in*

vii. *I would like an advocate to explain this again to me before I decide*

and

viii. *I understand I can change my mind at anytime*

Name……

Date……

Advocate Support: (if requested)

I confirm that I have talked to ……about the research project on Direct Payments. I believe they understand the nature of the project and have said

iv. I want to join in

v. *I understand I can change my mind*

vi. *I do not want to join in*

Advocate

Name……..Date……

Appendix 4: Focus Groups: Topic Guide

Topic No:	Theme(s) identified from Literature Search	Topic Guide for LD Focus Group	Topic Guide for Care Managers
1	• **Segregation/Institutionalisation** • Biological difference /Humanness Social/Economic inefficiency/Fixed innate IQ /Educational Failure/Social class • *Fear & Control (in the community too)*	• How are people with learning difficulties (you) seen by other people (family/neighbours/Professionals (staff)? • What do you think about 'labels' (disabilities/difficulties/people first? • Who has helped you most to achieve things (relationships/where to live/things to do/places to go? • What did you like about the way they helped/supported you? • Tell me how people can be unhelpful to you?	**Legacy of segregation & labelling** ○ What is your professional perception of people with learning disabilities? ○ How do you think they are perceived by the wider community? ○ How does this impact on your role? ○ Which people are important to people with learning disabilities and do you (how) involve them?
2	• **Care in the Community** • Changing research/ideas around IQ/Poor/Working Class • Post War Human Rights ideas/Welfare State/Economic Growth & decline • Parental campaigns for the right to	• Tell me about your experiences of 'services' during your life so far: - Where you have lived? - Who have you lived with? - What you have done during the day, evenings and weekends?	**The changing nature of community care – services to individual budgets** What does 'community

	education & services • Services to support families in their caring task (1971) • Deinstitutionalisation • *Care/dependency/Normalisation/ordinary lives in ordinary streets*	• What things have changed since you were younger? • What has been good/bad? • What about the next year/5/10years – what do you want to do/things to keep/to change?	care' mean to you and your role with people with LD? What have been the key changes in the last 10 years What has been the impact on people with LD? Your role?
3	**Valuing People** enable people with learning disabilities to have as much choice & control over their lives and the services and support they receive…..no	• Since 2001 (Valuing People) has your life changed in terms of: - Where you live? - Who you live with? - What you have done during the day, evenings and weekends?	**Managing Change** In the next 10 years what do you think people with LD will expect from you in your role?

	longer marginalised or excluded… *..new opportunities to live full and independent* *lives as part of their local communities*	• Tell me about the decisions you have made – easy/hard/who has helped you/how?	How do you evaluate the concept of the 'individual' that underpins personalisation?
4	**Individualisation/Independence/Rights/Control** • Direct Payments More choice & control, greater range of services • Individual Budgets**:** transparent resources, link funding streams, flexibility • (Personalisation: customer friendly existing services, giving people more say in how services are run, how money is spent, becoming co-designers/producers, self-organisation by society) • *Individual Service User/Citizen/Vulnerable Adult*	• Do you think you have more choice and control over your lives (you making the choices with more services to choose from)? • Who do you make these choices with? (partners/families/friends/professionals)? • Where are they made (discussion groups/ Partnership Boards/PCP/Review meetings? • Can anyone tell me of an important choice they have made recently – what was it/how/who with/how do you feel about it?	**Choice & Control** What is 'choice' for people for people with learning disabilities What is your professional role in the choice agenda How does it (if any) change your role with people with learning disabilities Who else (roles) need to embrace change to the benefit of people with LD How do you see risk and choice balanced out

5	**The Future** • *Healthy and safe citizens* • *Empowerment and inclusion (taking account of the complexity of social relations)*	Writers/Professionals/Parents suggest that if there are lots of changes for people with learning disabilities (because they have individual budgets and more choice over their lives) it is very important that they remain healthy and safe: • What do you think? • Who can support you and how? • When you think about the future who will be the important people in your lives, and how can they best support you?	**The future with individual budgets and Personalisation** Working in pairs (with flip chart) – looking forward in the work of your team. For professionals and then for people with LD; What looks: • Positive • Difficult? • Worrying

6	**Finally….**	- Today we have been talking about you, your lifestyle (what you do/what might change), and how you like to be helped with your decisions/choices; • Is there anything you think I have forgotten to ask, maybe something important to you but we have not mentioned it today?	

Appendix 5

1913 Mental Deficiency Act

The Radnor Commission's Report, (published in 1908) was based on evidence from 248 witnesses in 8 days of hearings (Thomson 1998, p.25), had four main outcomes for mental deficiency policy:

i. the establishment of a Board of Control;
ii. introduced four categories of mental deficiency;
iii. required local authorities to maintain mental deficiency institutions;
iv. established supervised community care and control;

The recommendations of the Commission's report led, after some time, to the 1913 Act. The four categories under the 1913 Mental Deficiency Act were:

Idiot: deeply defective in mind from birth or from an early age as to be unable to protect themselves from common dangers;

Imbecile: whilst not so defective as idiots, were still incapable of managing their own affairs;

Feeble-minded: not as defective as imbeciles but required *care, supervision and control* for their own protection or for the protection of others;

Moral Defectives: those from an early age display some permanent mental defect coupled with criminal or vicious personalities;

Families who wished to place their child in an institution required two medical certificates from qualified doctors, one of whom was to 'be approved' for this purpose by the local health authority or the Minister of Health. A range of people who believed someone was defective in their community, AND who might be in

need of care and training, or had been found guilty of a criminal offence, or was a habitual drunkard, or had been found incapable of receiving education at school could apply to the Board of Control to have that person sent to an institution. Again considerable power rested in medical hands as two medical certificates were required to support any application. What is interesting, as Race (2002, p.30) points out, is that although the categories are said to be medical classifications, in the sense that they would be identified by medical professionals, they are actually defining mental deficiency in terms of a social outcome, and there is no real measure of the extent of the defect itself.

The 1913 Mental Deficiency Act is often associated with institutional practice but, in setting out specific circumstances in which a mentally defective person could be brought to the attention of the Board of Control, the Act also provided for formal community care provision through licensing, guardianship and supervision. These provisions made 'community care' an option, available much earlier than the 1954 Royal Commission most commonly associated with community care (Walmsley & Rolfe (2001, p.62).

Appendix 6: Comparisons of *Better Services for the Mentally Handicapped* (1971) and *Valuing People* (2001)

(1971) *Better Services for the mentally Handicapped*	**(2001*) Valuing People* – a new strategy for learning disability for the 21st century**
Written by Civil Servants and favoured advisors	Written after an extensive consultation with people with LD and carers
Services for the handicapped member and family	People with LD having rights, independence, choice & inclusion
The handicapped person as nearly a normal life as handicaps will permit	Part of the mainstream & included
Full use made of available knowledge which can prevent or reduce the severity of mental handicap	Enforceable civil rights for disabled people
Meeting the handicapped person's needs for stimulation, social training and purposeful occupation or employment	Differing needs based on a starting presumption of independence
Detailed planning of services • Under-5's • Education at LA schools • Training Centres • Residential	Assumes a whole range of services with strategic objectives based around themes • Children & Young People • Choice & Control • Supporting Carers • Improving Health • Housing • Fulfilling Lives • Employment • Quality Services • Partnership Working • Implementation (Support Team)

Implemented by Professionals	Implemented by Partnership Boards
• Doctors • Nurses • Social Workers • Health Boards • Local Authorities	• Purchasers providers • Carers • Service users • Learning Disability Task Force
Funded from: • General increase in public spending on health & social services	Funded from: • Learning Disability Fund • Health act 'flexibilities' • Implementation Support Fund

Adapted from Race, D. (2007) A tale of two White Papers: Policy documents as indicators of trends in UK services. *Journal of Intellectual Disabilities, 11(1), pp.83-103.*

Appendix 7

Learning Disability Partnership Boards: A checklist of questions

(Adapted from 'Making Valuing People: strategies for change in services for people with learning disabilities: (2004) Fyson & Ward: Policy Press).

Powers of a Partnership Board and its members

- What powers does the LDPB have and what does it *not* have.
- Can it make any binding decisions; what has to be ratified elsewhere and why.

- If the LDPB makes a decision who is entitled to vote. Are there different entitlements to vote for people with learning disabilities and carers, and then professionals. What is the position of advocates and service providers at a LDPB.
- Who decides upon the Chair(s) – can a new chair be elected if members wish. Is there a co-chair with a learning disability.
- Explain the role and responsibilities of any senior officers or councillors attending LDPB, especially in relation to LDPB decisions and actions.
- Who sets the agenda and how to people (members and others) get items onto the agenda

Practical arrangements

- Accessible building, good acoustics, microphones available, room to split into small groups, car parking, good public transport to the meeting room
- Support available to enable people to attend
- Timing and length of meeting
- One LDPB or locality groups
- Expenses paid for people who attend

Representation

- Do people with learning disabilities and carers represent their 'population', and are there mechanism for them to consult and feedback on LDPB business. Is there time for them to discuss agenda items with their groups before the LDPB.

Accessible Information

- Is information presented and recorded in accessible ways

- Have people with learning disabilities and carers been involved in a recent review of the operation of the LDPB to see if they have any ideas for improving the effectives of the Board

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